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The Medical Foundation, Inc.
Boston, Massachusetts

FEASIBILITY OF DEVELOPING A COMPUTER-BASED HEALTH AND WELFARE INFORMATION SYSTEM FOR METROPOLITAN BOSTON

November 1968

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THE MEDICAL FOUNDATION, INC.

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Dear Mr. Smart:

As promised earlier, I am sending to you a copy of the final report of The Medical Foundation which was submitted to the Joint Center for Urban Studies of MIT and Harvard University as part of the overall study supported by the U.S. Public Health Service. The report is entitled "Feasibility of Developing a Computer-Based Health and Welfare Information System for Metropolitan Boston."

Once again, I wish to express my thanks to you and your staff for your assistance during the conduct of the study.

Sincerely yours,

John H. Noble

John H. Noble, Ph.D.
Project Director
Health Information Study

JHN:al
Enclosure

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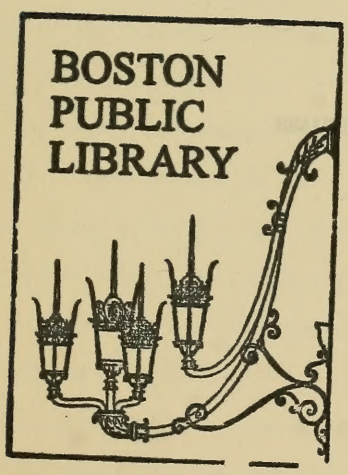

by

JOHN H. NOBLE, JR., Ph.D.

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November 1968

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This study is the result of the cooperative efforts of a great many people. The Medical Foundation, Inc., wishes to thank all respondents for their contributions. To name and to acknowledge the contributions of only a few would not do justice to all. The high rate of response and the care with which individuals replied to the various inquiries in this study indicate the scope of acknowledgement due.

The study was conducted under a subcontract with the Joint Center for Urban Studies of MIT and Harvard University as part of a prime contract (PH-110-234) of the U.S. Public Health Service to the Joint Center. Dr. Daniel P. Moynihan was principal investigator, and Dr. James S. Beshers and Dr. Victor W. Sidel were co-principal investigators.

Dr. Ralph Notman, director of Mental Health Center Studies, Boston University Medical School, and former president of the Council on Social Data Systems, Inc., and Dr. Harold W. Demone, executive director of United Community Services of Metropolitan Boston and former executive director of The Medical Foundation, Inc., together with Dr. Moynihan and Dr. Beshers, collaborated in formulating the problem, writing the proposal, and negotiating the contract with the U.S. Public Health Service.

The Council on Social Data Systems, Inc., and the Joint Center for Urban Studies of MIT and Harvard University were co-sponsors of the study.

The Medical Foundation wishes to acknowledge with appreciation the support and assistance it has received from these sources and from the staff of the Joint Center.

The Medical Foundation has made every effort to report and interpret data in an unbiased manner. Although indebted to many, it must assume responsibility for the contents of this report.

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CHAPTER I

INTRODUCTION AND OVERVIEW OF THE HEALTH AND WELFARE INFORMATION SYSTEM FEASIBILITY STUDY

In September 1967, The Medical Foundation, Inc., began a 15-month study to determine the ability and willingness of health organizations and related agencies in Metropolitan Boston to participate in a community-wide health and welfare information system.

The feasibility study, conducted under a subcontract with the Joint Center for Urban Studies of MIT and Harvard University, was undertaken because it seemed particularly relevant to The Medical Foundation's policy of supporting, stimulating, and influencing more effective community efforts in the health field in the Boston area.

Health and welfare planners and administrators have long desired access to comprehensive health and welfare statistics in order to guide program planning, development, and administration. Statistics reflecting present use of facilities and services--yet sensitive enough to measure changes in demand and utilization patterns--are considered necessary for reaching rational decisions

to improve health and welfare services.[1]

This long-standing desire of planners and administrators provided the impetus for the present study. The Medical Foundation has taken every precaution to insure objectivity. Responsibility to the broader community precludes the advocacy and promotion of special interests or current fashions. There has been no attempt to "sell" a computerized health and welfare information system to the organizations which agreed to participate in the study.

At times, it has been difficult for the staff of the Health Information System Feasibility Study to avoid playing a consultative role. Some executives sought advice regarding the specific types of information and information linkages among agencies they should seek for planning, research, or evaluation. To avoid contamination of responses, feedback and advice were avoided until respondents had stated their untutored opinions and preferences.

As is customary in the conduct of research, The Medical Foundation has protected the confidentiality of respondents. Organizations identified in nine in-depth studies of health and welfare information systems participated with the knowledge that their identities would be known. In general, organizations have been grouped by type and their aggregated responses reported.

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[1] See John D. Thompson, "A Comprehensive Utilization and Patient Information Statistical System" (paper presented at the Regional Medical Program Conference Workshop, Washington, D.C., Jan. 17, 1968), p. 1.

Although a tentative list of health and health-related agencies which were to be considered for study by The Medical Foundation is presented in an appendix,[2] it is not possible to extrapolate unambiguously from this list to the organizations actually studied within each organizational type.

The Medical Foundation, within the broad construction of its subcontract with the Joint Center for Urban Studies of MIT and Harvard University, has asked questions and chosen methods of investigation calculated to yield unbiased data. The study was conducted in as close collaboration with the staff of the Joint Center as feasible. The Medical Foundation, however, must assume responsibility for the final report.

In this report, issues relating to the feasibility of establishing a community-wide health and welfare information system have been studied from a special vantage point. Although few would deny the merit of establishing an information system for collecting, processing, and analyzing comprehensive health and welfare data to assist planners and administrators to improve services to those in need of care, certain questions still remain. Can it be done? And if it can, under what conditions?

One approach to feasibility attempts to establish a system--perhaps on a pilot basis. To the degree that the enterprise succeeds, it is considered feasible. Over a period of time,

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[2]See Appendix A.

failure to achieve self-support or continued Federal funding becomes the measure of unfeasibility. Another approach--akin to marketing research--attempts to determine the receptivity of potential consumers to a possible new product. It is this approach to feasibility which The Medical Foundation has taken. Emphasis has been placed on learning whether potential participants in a community-wide health and welfare information system would be willing to participate, what preferences they have for alternate forms of a system, and what types of data they feel they would be able to contribute. This approach yields evidence as to whether a market exists and gives some assurance that the enterprise, if undertaken, has a chance of success.

It should be clear from the outset that the potential consumers of health and welfare statistics are not a homogeneous group. Planners, administrators, and researchers have different roles to play, are burdened with different types of responsibility, and have different degrees of power. It is believed that these variables influence interest and responsiveness to alternate proposals for a community-wide health and welfare system.

This study has assumed that the attitudes and opinions of executives of health and welfare organizations are of critical importance in judging feasibility. Their support is considered essential if a successful system is to be developed. Experience shows that planning and research endeavors which fail to win support of administrators usually do not succeed at all in the long run.

Therefore, executive needs, desires, and conditions to participation are considered paramount in this report. It is felt that attempts to bypass this consumer group would set the stage for failure.

Although health statistics and organizations providing health services have been primary foci of investigation, social welfare statistics and organizations have not been neglected. They have been considered "health-related organizations," thereby recognizing the overlap of the health, welfare, and social service domains.

This feasibility study actually embraces four substudies, each asking a different set of questions and employing different methodologies. The first was a telephone inquiry designed to gain some idea of the record keeping and processing resources in selected health and related organizations in Metropolitan Boston.

The second study sought in-depth knowledge of one or more selected information systems in a limited number of organizations chosen because of their importance, leadership potential and influence, interest in community-wide information linkage, or experience in modern techniques of data processing.

A third study investigated the degree to which information presently seen as needed by selected health and welfare agencies is compatible in form and definition.

Finally, executive reactions to proposals for developing a computer-based health and welfare information system were explored.

In effect, these substudies ask questions and draw forth

answers regarding the human side of the man-machine equation of computerized information systems. The state of computer technology available for developing a community-wide health and welfare information system is the subject of a separate report of the Joint Center for Urban Studies of MIT and Harvard University.

CHAPTER II

SUMMARY OF CONCLUSIONS AND RECOMMENDATIONS

Introduction

Critical issues face any group which wishes to design and develop a health and welfare information system, regardless of the scope of the system intended. These issues are philosophical, methodological, political, and economic in character. Some of the serious questions they raise are:

- Which attributes and qualities of people, organizations, and geographic areas should be measured for what purposes?

- Can these attributes and qualities be measured so that they are sufficiently reliable and valid to attain the specified objectives?

- Will people who--and organizations which--control access to needed information make it available to the system?

- If some people and some organizations will not share needed information about themselves or the organizations, how many must cooperate to permit valid inference and adequate control for bias?

- Faced with competition for scarce resources of money, technical manpower, and machines, should policy makers accept a

system designed to collect information on whole universes of people, organizations, and geographic areas? Or can sampling and periodic surveys achieve the same results more efficiently?

- For any specific set of data, what are the relative costs associated with alternative modes of collecting, processing, and promulgating findings?

- Does there exist a sufficient number of potential users to justify the cost of developing and maintaining a system--and will these potential users support a system financially and politically?

While these questions cannot be answered easily, they obviously deserve careful consideration by systems designers and developers. Excellence of design and likelihood of successful implementation depend upon how well these questions are answered.

This chapter of the report presents conclusions and recommends courses of action consonant with them. These conclusions and recommendations answer in a rough, pragmatic fashion some of the broadly stated questions just raised. In effect, they limit the degree of freedom available to systems designers and developers who might wish to see the most comprhensive health and welfare information system possible established in Metropolitan Boston.

Undoubtedly, the Health Information System Advisory Committee of the Joint Center for Urban Studies will take these conclusions and recommendations into consideration as they guide the Joint Center staff in designing a preliminary health and welfare

information system for Metropolitan Boston. Other considerations may also influence the course which will be taken.

Conclusions

---- How large an enterprise is record keeping and processing in health and related organizations in Metropolitan Boston?

The inventory of record keeping and processing indicates that it is a very large enterprise, involving hundreds of people, requiring specialized organizational structures, and costing many thousands of dollars. Larger organizations, especially hospitals, spend hundreds of thousands of dollars on record keeping and processing.

With few exceptions, the group of organizations comprising the larger and medium-size hospitals, planning organizations, registry and regulatory boards, university-related agencies, and state research and statistical units spend the most money on record keeping and processing. They employ the greatest number of full- and part-time people in individual records, accounting, and automatic data processing (ADP).

Judging from the magnitude of the investment, record keeping and processing play a vital role in the day-to-day operation of health and related organizations in Metropolitan Boston.

---- How automated is record keeping and processing in health and related organizations in Metropolitan Boston?

At present, automation has not taken hold to any great extent.

Only the very largest organizations can afford an in-house computer. On the other hand, more and more medium and small organizations are beginning to use keypunches and sorters. There is a growing awareness of what automation can do. A number of organizations are considering outside service organizations as the solution to their data processing problems.

The same group of organizations which spends the most money and employs the greatest number of people in record keeping and processing--namely, the larger and medium-size hospitals, planning organizations, registry and regulatory boards, university-related agencies, and state research and statistical units--have the most expertise in use of ADP. They also have machine-readable data, although clarification is needed about the amount of data which is relevant. Very little is susceptible to record-linkage on an individual or geographic basis.

These same organizations have greater access to in-house computers and/or they make more staff-initiated applications of the computer than other health and welfare organizations; that is, their staffs either contract with others to program jobs on a computer or their staffs program the jobs themselves.

It is necessary to recognize, however, that this group of organizations has only a relatively superior position in the use of ADP and/or the computer. Expressed in absolute numbers, four of the nine largest hospitals had an in-house computer, four an ADP

department, and two made staff-initiated applications of a computer located outside their organizations. Of the 37 medium-size hospitals, seven had an in-house computer, four an ADP department, and five made staff-initiated applications of a computer.

The four state research and statistical units and three registry and regulatory boards, all together, had one in-house computer, two ADP departments, and two staff-initiated applications of a computer. Among the 20 planning agencies, two had an in-house computer, three an ADP department, and eight used computers on staff initiative. Of 14 university-related agencies, two had in-house computers, none had a separate ADP department, and 12 used computers on staff initiative.

Thus, when viewed in absolute terms, the relative superiority or greater expertise in use of ADP and/or the computer of these organizations does not indicate that data processing has had a very great impact. Furthermore, it implies that there has been virtually no impact upon most of the other organizations surveyed. These include the private and public social agencies, local welfare departments, nursing homes, visiting nurse associations, local health departments, and mental health clinics.

---- How great an impact is automation likely to have on record keeping and processing in health and related organizations in Metropolitan Boston during the next three to five years?

There are developments taking place which are likely to accelerate the rate of change. Many organizations, unable to afford

automation by themselves, will be exposed to its benefits through membership in one of the computer-based information subsystems serving specialized interests now under development in Metropolitan Boston. For example, the Massachusetts Blue Cross Utilization Review and Provider Service System is fast becoming the nucleus of a hospital health information system. United Community Services of Metropolitan Boston plans to develop a system for voluntary social agencies in the area. The executive office of administration and finance of the Commonwealth of Massachusetts is actively considering the requirements for a system serving all state agencies. Finally, the office of the attorney general is planning a "crime-puter" to serve the intelligence requirements of the law enforcement system.

These developments represent a vertical stratification and consolidation of interests. Horizontal linkages among the developing subsystems assume secondary importance during this period of consolidation. For those who would like to see more immediate provision for horizontal linkages, these developments may appear disadvantageous. However, this is not necessarily the case.

Considerable housecleaning must be done before organizations can sort out and identify the information they need for their administrative purposes, the information they should pool with similar organizations for planning and research purposes, and the compatible measures they should adopt to obtain various types of information. The struggle which organizations joining information

subsystems must undergo to reach decisions in these matters will improve and purify the data base upon which horizontal linkages can be built.

By the same token, problems of individual confidentiality and corporate privacy, which loom large when considered within the context of horizontal linkage, may be less trying later. In the years to come, the courts may provide legal precedents which will define the limits to which organizations may go in sharing information among themselves.

---- How much of a tradition exists among health and related organizations in Metropolitan Boston for sharing information?

The present study has shown that there is little tradition to speak of. Compacts or special agreements facilitating exchange of information between agencies are rare. The most notable example--the Social Service Exchange--recently ceased operation largely because a significant number of member agencies failed to live up to their agreement to register all clients served by them. This, of course, rendered searches by other member agencies inconclusive. Neither is there any standard policy for releasing information.

These missing elements--lack of special agreements facilitating exchange of information and lack of a standard policy for releasing information--are assumed to be important criteria for identifying groups of organizations naturally suited for linkage into subsystems. Under the circumstances, the basis for establishing artificial linkages is not clear.

---- Is the concept of a community-wide health and welfare information system acceptable to executives?

There is polite, positive acceptance among the majority of executives. Only a fifth of the executives had negative reactions to the concept of a community-wide health and welfare information system.

---- Are executives of health and related organizations in Metropolitan Boston willing to participate in a system if it should become a reality?

By the most favorable interpretation, 60 percent of the executives approached indicated willingness to participate in some form of a health and welfare information system; one-third reacted negatively to the proposal. In many instances, willingness to participate was expressed in terms of using information a system might provide rather than sharing information.

With respect to the form which executives would like to see a system take, one-third or less stated preference for one of the forms proposed--a directory of information stored in various agencies, a central registry or exchange identifying patients and clients, or an archive in which are stored abstracts of health, welfare, and social agency records on individuals served.

---- Is it possible to compare information in its present form gathered by health and welfare organizations in Metropolitan Boston?

From the standpoints of compatibility of definitions and the possibility of individual- and geographic-based record linkage, it is apparent that most files of information now maintained in health and welfare organizations are so incompatible that comparisons cannot be made between sets of data derived from different organizations--and often not even between sets of data gathered by different divisions of the same organization.

Of course, it is important to bear in mind that this conclusion is based upon analyses of 114 forms of nine selected health and welfare information systems and of 139 forms of 13 divisions of the Massachusetts Department of Public Health. It is not inconceivable (but improbable) that other health and welfare organizations in Metropolitan Boston may have achieved greater compatibility of definitions in the information they are gathering.

Recommendations

Cumulatively, the conclusions reached guide The Medical Foundation, Inc., in presenting recommendations to the Health Information System Advisory Committee and to the staff of the Joint Center for Urban Studies of MIT and Harvard University. They are as follows:

1. It is recommended that emphasis be placed on creating a blueprint for the one form of a system which seems most feasible at this time--a directory of information stored in

various agencies. This directory would be made available to authorized persons.

A system which adequately maps and keeps up to date the characteristics of information in existing files would assist organizations in conducting needed housecleaning. Such a system also would assist the information subsystems now developing along lines of vertical cleavage to keep track of what is happening outside of their immediate environment.

2. It is urged that the temptation to scatter energy by designing several alternative systems be resisted. It is clear that it will be necessary to provide much education and to answer many legal questions before it becomes possible to build comprehensive community-wide health and welfare information systems in the form either of central registries identifying patients and clients or of archives in which are stored abstracts of health, welfare, and social agency records.

In view of the very large costs involved in developing and maintaining such systems, it is doubtful that they should receive high priority. There are too many competing demands for scarce resources in the health and welfare fields.

3. In line with the recommendation that the Joint Center staff concentrate on designing a blueprint for a directory of information stored in health and welfare agencies

(computerized if necessary), the matter of organizing, staffing, and supporting a central agency to serve as a conduit between information subsystems deserves careful attention.

The possibility of placing the Council on Social Data Systems (or another nondenominational body of interested health and welfare professionals) on a sound financial basis so that it may obtain staff to function as the central agency should be thoroughly explored.

4. In view of the political climate and the ethical problems associated with individual record linkage using either social security number or name, exact birth date, and birthplace, it is recommended that no system be designed that would include such capabilities.

It is apparent that a significant portion of the community--political, lay, and professional--fears so powerful a system. Because of the risks involved, it is doubtful that such a system would be countenanced.

5. It is recommended, therefore, that high priority be placed upon determining the strengths and limitations of aggregate data and statistics which may be obtained from health and welfare organizations for administrative, planning, and research purposes.

6. It is also recommended that the burden of proof be placed upon planners, administrators, and researchers to show usefulness of information in relation to the cost of obtaining this information in varying degrees of aggregation.

7. In areas where data considered valuable for administrative, planning, and research purposes are missing, it is recommended that the cost-benefits of sampling and special surveys be compared with the cost-benefits involved in erecting and maintaining information systems which process data derived from total universes of people, organizations, and geographic areas.

8. It is strongly recommended that the staff of the Joint Center explore the full capabilities, costs, and legal issues of geographic-based record linkage. It may be a solution to the major problems of confidentiality. It is unclear, however, whether residual legal issues remain.

Many organizations, including Blue Cross in its Utilization Review and Provider Service System, do not encode exact street address. How much more would it cost to add exact street address to the Blue Cross Utilization Review and Provider Service System in order to achieve flexible geographic-based record linkage? What inducements does Blue Cross require to incorporate exact street address into its system?

9. If the decision is reached to go ahead in the development of a system, it is urged that small demonstrations be made the major program component for the first few years.

Demonstrations should show: (1) the ability of computer locks to safeguard confidential records as well as human personnel presently do; (2) the extent to which files of data, varying in degrees of completeness, can be used to generate useful aggregate statistics; and (3) the ability of a small operating system to become self-supporting through fees for service.

10. More generally, it is recommended that all health organizations and related agencies in Metropolitan Boston and other areas wishing to achieve compatibility between their service statistics and general population statistics be urged to incorporate 10 items of information as defined by the Bureau of the Census into their records. The items are: (1) relationship to head of household, (2) color or race, (3) age (month and year of birth), (4) sex, (5) marital status, (6) state or country of birth, (7) years of school completed, (8) employment status, (9) occupation, and (10) either year moved into present dwelling unit or place of residence five years ago.

It is not recommended that income be sought because it is practically impossible to obtain income figures reliably

and without resentment outside of a bank, finance company, or office of the Internal Revenue Service.

11. It is further recommended that these agencies be urged to incorporate into their records exact address by number, street, and city or town in preparation for flexible geographic-based record linkage by means of the DIME (Dual Independent Map Encoding) file or other computerized address coding scheme.

It is critical that these recommendations be adopted by the first health, welfare, and police subsystems that emerge in Metropolitan Boston and the state. Decisions reached by these subsystems are likely to shape the future for some time to come.

CHAPTER III

ABILITY AND WILLINGNESS OF ORGANIZATIONS TO PARTICIPATE IN A COMPUTER-BASED HEALTH AND WELFARE INFORMATION SYSTEM

Introduction

During the last week in May and the first week in June 1968, a letter[1] was sent to 181 executives of organizations previously contacted during the inventory stage of study--and to two other individuals later identified as significant spokesmen in the health field.

The letter asked three questions. These were, in essence:

1. Could your organization participate in a computer-based health and welfare information system assuming the form of:

    a) A directory of information stored in various agencies which could be made available to authorized persons?

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[1] See Appendix B for a copy of the letter. The number of executives to whom the letter was sent (183) differs from the number of organizations and individuals contacted during the inventory stage of study (186). Letters to the departments of city planning of MIT and Harvard University were not sent at the request of the Joint Center staff. One other letter to the Dorchester Area Planning Council was not sent because telephone inquiry had established that it had no staff.

b) A central registry or exchange identifying patients and clients on whom additional information could be obtained by contacting the organizations serving them?

c) An archive in which are stored abstracts of health, welfare, and social agency records on individuals served?

2. What types of information could your organization contribute to a health and welfare information system, whatever its form?

3. Under what auspices do you think a computer-based health and welfare information system serving Metropolitan Boston could best be developed?

By November 1, 1968, 150 replies to the letter had been received. This 83 percent rate of response is higher than usual for a mail inquiry.

As a matter of fact, the 150 replies represent more than an 83 percent response rate, since certain executives have jurisdiction over a number of divisions contacted during the inventory phase, or they have acquired jurisdiction over what used to be autonomous organizations. The commissioner of the Massachusetts Department of Public Health, for example, has jurisdiction over the five divisions of the Department separately inventoried; the commissioner of the Massachusetts Department of Public Welfare now has jurisdiction over what had been autonomous local welfare

departments. The reply of the commissioner of the Massachusetts Department of Mental Health covers all mental health hospitals and clinics under state jurisdiction.

Although the replies of the commissioners may carry more weight than those of subordinate executives and staff, lower echelon executive reactions have been reported unchanged in order to preserve the true picture of differing opinion which, in fact, exists within state departments and their jurisdictions.

Replies have not always come in the form of a letter. Some executives wished to speak directly to the Medical Foundation staff. Others sought clarification by telephone before writing. In some cases, respondents wished to give their reply over the telephone. Based upon the various forms of contact, there is little reason to believe that respondents did not understand the message communicated by letter.

Comparison of letter replies and transcripts of personal interviews and telephone conversations reveal no substantial difference in types of response--with one exception. Personal and telephone interviews forced respondents to address themselves to every question in all its parts. Letter replies could ignore or avoid answering parts of questions.

In July 1968, when 40 percent of the respondents had replied, preliminary analysis disclosed exceptionally favorable trends. At that point, the meaning of nonresponse was thought to be a sign of indifference, unwillingness to take or make known a position, or

inability to take time in a busy schedule to reply. Unwillingness to make known a negative position was not considered as an explicit possibility.

Followup and sequential analysis of replies indicate that late replies tend to be more negative than earlier replies. For example, only 9 percent of the respondents who had replied by July 1968 were negatively disposed toward the concept of a community-wide health and welfare information system. Final tally, however, indicates that 21 percent of the respondents do not accept the notion. Similarly, whereas 16 percent of the initial respondents reported unwillingness to participate in a system, later replies show that actually 32 percent are not willing to participate. These trends toward negativism hold for most types of organizations.[2] The trend is reversed, however, for public and private social agencies.

These results of sequential analysis are not unlike those of other opinion surveys which have found that early respondents are different from late and nonrespondents.

It is believed that the remaining nonrespondents in the present inquiry are at least as negative as the late respondents. One should bear in mind, therefore, that there is a probable positive bias in the following findings: (a) 71 percent of the executives accept the concept of a community-wide health and welfare

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[2]See Definitions, Chapter V, for a discussion of the organizational classification scheme employed in this study.

information system and (b) 60 percent of the executives are willing to participate in a health and welfare information system.

Replies go the gamut from acceptance and hearty endorsement through neutrality to varying degrees of rejection. A few executives claimed that a community information system was inapplicable to the needs of their organizations.

The first question, asking whether an organization could participate in one or more forms of a health and welfare information system, was formulated after considerable experimentation.

Various direct attempts to elicit "user specifications" made apparent the need to present alternative models rather than to ask open-ended questions. As a matter of fact, the open-ended approach tended to provoke rambling, non-focused discourses or so many requests for clarification that words were literally being placed in the mouths of some executives. A couple went so far as to say, "You're the expert. Tell me."

As a consequence, three models, based upon extant systems and presenting varying degrees of risk for the maintenance of patient and client confidentiality, were proposed. Their presentation to executives was expected to yield information delineating the most feasible form for a health and welfare information system in Metropolitan Boston and the kinds of resistance which each form, if attempted, might provoke.

Replies to the letters in many instances went beyond the three questions asked. Respondents indicated, in effect (1) whether

they were favorably disposed toward the concept of a computer-based health and welfare information system; (2) whether they would consider participating in such a system if it became a reality; (3) what form of a system they preferred; (4) what kinds of data they could contribute; and (5) under what auspices they thought a system could best be developed.

Willingness to participate was interpreted to imply tentative commitment to participate in or cooperate with a system within the constraints imposed by law, organizational policy, finances, and manpower. Favorable disposition toward the concept of a health and welfare information system--in contrast to willingness to participate--was judged both from the explicit answers and from the general tone of replies.

Analysis of executive response to the questions follows. In some instances, there are discrepancies in the number of replies to the various questions. This occurs because some executives did not answer each question fully. Again, some answers were too vague to permit clear interpretation of meaning. No attempt was made to "second guess." The analysis excludes ambiguous replies. It relies on specific or expressly implied responses to the questions.

Acceptability of the Concept of a Community-Wide Health and Welfare Information System

As shown by Table 1, 71 percent of the executives replying to the letter of inquiry were favorably disposed toward the concept of a community-wide health and welfare information system. Twenty-

TABLE 1

ACCEPTABILITY OF THE CONCEPT OF A COMMUNITY-WIDE

HEALTH AND WELFARE INFORMATION SYSTEM

Type Organization	N[a]	Response			
		Positive %	Negative %	Neutral %	Non-Applicable %
Hospitals	44 (54)[b]	82	16	2	0
Planning agencies	19 (22)	79	0	0	21
University-related agencies	9 (13)	78	0	0	22
Public social agencies	8 (8)	63	12	12	12
Local welfare depts.	6 (6)	83	17	0	0
Visiting nurse assns.	10 (11)	70	20	0	10
Private social agencies	11 (14)	64	36	0	0
Nursing homes	5 (6)	20	80	0	0
Mental health clinics	20 (24)	65	30	0	5
Local health depts.	9 (14)	44	56	0	0
Registry/regulatory boards	5 (7)	80	20	0	0
State research/statistical units	4 (4)	75	0	0	25
TOTAL	150 (183)	71	21	1	7

[a] N refers to the total number of organizations for which information was available for computing the percentages reported. Percentages have been rounded to the nearest whole number.

[b] N in parentheses refers to total number of organizations to which letters were sent.

one percent were opposed to such a system; one percent of the respondents were indifferent; and 7 percent claimed that a health and welfare information system was inapplicable to the needs of their organizations.

Assuming that executives speak for their organizations, hospitals, local welfare departments, planning agencies, university-related agencies, and state registry and regulatory boards are most favorably disposed toward a system. About 80 percent of these organizations endorsed the concept of a community-wide health and welfare information system. Least favorably disposed to a system are nursing homes and local health departments. The margin of opposition to a system rises above 50 percent for these latter types of organizations.

Mental health clinics and private and public social agencies are fairly ambivalent toward development of a community-wide health and welfare information system. Mental health clinics favoring a system emphasized that their support is contingent upon suitable safeguards for client confidentiality. Of the 20 mental health clinics answering the letter of inquiry, 13 favored, 6 opposed, and one did not think a system would be applicable to its needs. Of 11 private social agencies, seven favored and four opposed a system. Of eight public social agencies, five favored, one opposed, one was indifferent to the concept, and one considered a system inapplicable to its needs. The opposing agencies cited their desire to protect individual rights to privacy as the reason for rejecting a system.

Willingness to Participate in an Information System

Replies to letters sent to 183 executives of health and related organizations in Metropolitan Boston permit judgment on their willingness to participate in a community-wide health and welfare information system. Willingness to participate implies a tentative commitment to participate in or cooperate with a system within constraints imposed by law, organizational policy, finances, and manpower.

As shown by Table 2, 60 percent of the responding executives would be willing to participate in a system; 32 percent would not participate; one percent expressed indifference; and seven percent regarded a system as inapplicable to their needs. It is evident that roughly 10 percent fewer respondents are willing to participate in a system than accept the concept of a community-wide health and welfare information system (60 percent willing to participate versus 71 percent accepting the concept).

Seventy percent or more of the university-related agencies, public social agencies, state registry and regulatory boards, state research and statistical units, and planning agencies expressed willingness to participate in a system. Local welfare departments, nursing homes, and local health departments were least willing to participate in a system. Hospitals, visiting nurse associations, and private social agencies appeared ambivalent about participation. Roughly one-third to one-half of these organizations gave notice of their unwillingness to participate in a system. However, two hospitals unwilling to participate currently indicated

TABLE 2

WILLINGNESS TO PARTICIPATE IN A COMMUNITY-WIDE

HEALTH AND WELFARE INFORMATION SYSTEM

Type Organization	N[a]	Response			
		Positive %	Negative %	Neutral %	Non-Applicable %
Hospitals	44 (54)[b]	61	34	5	0
Planning agencies	19 (22)	68	11	0	21
University-related agencies	9 (13)	78	0	0	22
Public social agencies	8 (8)	75	12	0	12
Local welfare depts.	6 (6)	17	83	0	0
Visiting nurse assns.	10 (11)	60	30	0	10
Private social agencies	11 (14)	55	45	0	0
Nursing homes	5 (6)	20	80	0	0
Mental health clinics	20 (24)	65	30	0	5
Local health depts.	9 (14)	33	66	0	0
Registry/regulatory boards	5 (7)	80	20	0	0
State research/statistical units	4 (4)	75	0	0	25
TOTAL	150 (183)	60	32	1	7

[a]N refers to the total number of organizations for which information was available for computing the percentages reported. Percentages have been rounded to the nearest whole number.

[b]N in parentheses refers to total number of organizations to which letters were sent.

willingness to consider participation at a later date after they had established adequate internal information systems for their own purposes.

Again, individual confidentiality was the reason most often cited for refusal to participate. One private social agency stated conditional opposition on these grounds; it would oppose development of a community health and welfare information system until assured that individual confidentiality was properly safeguarded.

Favored Auspices for an Information System

The query concerning which auspices was favored for development of a community-wide health and welfare information system met with indifference and scant opinion. As shown by Table 3, almost 50 percent of the respondents would venture no opinion or expressed indifference. Few executives preferred state or Federal auspices or some combination of public and voluntary auspices. Twenty-nine percent of the respondents stated a positive preference for development of a system under voluntary auspices. Another seven percent excused themselves from responding to the question on the grounds that a health and welfare information system was inapplicable to their situation.

This apparent lack of concern about auspices probably results from the abstract nature of the question asked about preferred auspices. Undoubtedly, this apolitical stance will change as

TABLE 3

FAVORED AUSPICES FOR A COMMUNITY-WIDE

HEALTH AND WELFARE INFORMATION SYSTEM

Type Organization	N[a]	Auspices				
		State/ Federal %	Voluntary %	Combina- tion %	No Response/ Neutral %	Non- Applicable %
Hospitals	44 (54)[b]	16	39	7	39	0
Planning agencies	19 (22)	16	16	5	42	21
University-related agencies	9 (13)	0	44	11	22	22
Public social agencies	8 (8)	25	0	25	38	12
Local welfare depts.	6 (6)	17	17	0	66	0
Visiting nurse assns.	10 (11)	0	50	0	40	10
Private social agencies	11 (14)	0	45	0	55	0
Nursing homes	5 (6)	0	20	0	80	0
Mental health clinics	20 (24)	5	40	5	45	5
Local health depts.	9 (14)	11	0	11	77	0
Registry/regulatory boards	5 (7)	40	0	0	60	0
State research/statistical units	4 (4)	0	0	0	75	25
TOTAL	150 (183)	11	29	6	47	7

[a]N refers to the total number of organizations for which information was available for computing the percentages reported. Percentages have been rounded to the nearest whole number.

[b]N in parentheses refers to total number of organizations to which letters were sent.

specific organizations jockey for the position of leadership in the development of a system for Metropolitan Boston.

Preferred Form for an Information System

Many executives made known only their general willingness or unwillingness to participate in a system. Of those willing to participate, few systematically responded to the precise question of which form or forms they would like to see the system assume. Because stated preference for one form of a system does not necessarily exclude the others, tabulating replies to this question was difficult. Only explicit rejection of a given form would suffice for valid exclusion.

Accordingly, each reply to the question was coded as positive, negative, or as no response and neutral. The latter category encompassed neutral statements, evasive replies, and no reply at all. In this way, it is possible to glean from the data the salient theme or tendency--if present.

As previously noted, the three forms of a community-wide health and welfare information system presented to executives for consideration were:

1. A directory of information stored in various agencies which could be made available to authorized persons.
2. A central registry or exchange identifying patients and clients about whom additional information could be obtained by contacting the organizations serving them.

3. An archive in which are stored abstracts of health, welfare, and social agency records on individuals served.

As shown by Table 4, 33 percent of the executives would like to see the system assume the form of a directory of information stored in various agencies; 32 percent would not favor such a directory; and 28 percent did not address themselves to the question or were neutral.

Nursing homes, state research and statistical units, local health departments, and mental health clinics appear more negatively disposed toward a directory form of a system than other types of organizations. Public social agencies were most favorably disposed toward a directory.

With respect to a central registry form of an information system, Table 5 indicates that 30 percent of the executives favor such a system. Thirty-six percent reject the idea; and 27 percent did not address themselves to the question or were neutral.

Nursing homes, local health departments, and private social agencies were most opposed to a central registry. Visiting nurse associations, mental health clinics, and, to a degree, hospitals appear evenly divided in opinion. State research and statistical units, university-related agencies, and public social agencies tend to favor a central registry more than other types of organizations.

TABLE 4

PREFERENCE FOR DIRECTORY OF INFORMATION SOURCES

Type Organization	N[a]	Response: Positive %	Negative %	No Response/ Neutral %	Non-Applicable %
Hospitals	44 (54)[b]	36	25	39	0
Planning agencies	19 (22)	42	16	21	21
University-related agencies	9 (13)	44	22	11	22
Public social agencies	8 (8)	63	12	12	12
Local welfare depts.	6 (6)	0	17	83	0
Visiting nurse assns.	10 (11)	30	40	20	10
Private social agencies	11 (14)	18	36	45	0
Nursing homes	5 (6)	20	80	0	0
Mental health clinics	20 (24)	35	45	15	5
Local health depts.	9 (14)	33	56	11	0
Registry/regulatory boards	5 (7)	0	20	80	0
State research/statistical units	4 (4)	0	75	0	25
TOTAL	150 (183)	33	32	28	7

[a] N refers to the total number of organizations for which information was available for computing the percentages reported. Percentages have been rounded to the nearest whole number.

[b] N in parentheses refers to total number of organizations to which letters were sent.

TABLE 5

PREFERENCE FOR CENTRAL REGISTRY OF

PATIENTS AND CLIENTS

Type Organization	N[a]	Response			
		Positive %	Negative %	No Response/ Neutral %	Non-Applicable %
Hospitals	44 (54)[b]	32	27	41	0
Planning agencies	19 (22)	21	42	16	21
University-related agencies	9 (13)	56	0	22	22
Public social agencies	8 (8)	50	25	12	12
Local welfare depts.	6 (6)	0	17	83	0
Visiting nurse assns.	10 (11)	40	40	10	10
Private social agencies	11 (14)	9	64	27	0
Nursing homes	5 (6)	20	80	0	0
Mental health clinics	20 (24)	40	45	10	5
Local health depts.	9 (14)	11	66	22	0
Registry/regulatory boards	5 (7)	0	20	80	0
State research/statistical units	4 (4)	75	0	0	25
TOTAL	150 (183)	30	36	27	7

[a] N refers to the total number of organizations for which information was available for computing the percentages reported. Percentages have been rounded to the nearest whole number.

[b] N in parentheses refers to total number of organizations to which letters were sent.

Table 6 shows that almost twice as many executives oppose development of an archive in which are stored abstracts of health, welfare, and social agency records as favor it. Forty-one percent of the executives react negatively to the proposal to develop an archive; 24 percent would like an archive; and 28 percent did not answer the question or were neutral.

Nursing homes, mental health clinics, local health departments, and both private and public social agencies tend to oppose an archive more than other types of organizations. Only state research and statistical units indicated strong support for an archive.

Seven percent of all respondents disqualified themselves from answering these questions because they felt a health and welfare information system had no applicability to their organizations.

Willingness to Contribute Various Types of Data

Executives tended to respond in an unsystematic fashion when asked to indicate what types of data their organizations could contribute to a community-wide health and welfare information system. Replies to this question, therefore, have been coded as positive, negative, or as no response and neutral in the same way that executive response to the question of preferred form for a system was analyzed.

Executives were asked whether their organizations could contribute the following types of data to a system:

TABLE 3

PREFERENCE FOR ARCHIVE OF ABSTRACTS

Type Organization	N[a]	Response: Positive %	Negative %	No Response/ Neutral %	Non-Applicable %
Hospitals	44 (54)[b]	23	36	41	0
Planning agencies	19 (22)	26	32	21	21
University-related agencies	9 (13)	33	22	22	22
Public social agencies	8 (8)	38	50	0	12
Local welfare depts.	6 (6)	0	33	66	0
Visiting nurse assns.	10 (11)	30	40	20	10
Private social agencies	11 (14)	9	55	36	0
Nursing homes	5 (6)	0	80	20	0
Mental health clinics	20 (24)	25	60	10	5
Local health depts.	9 (14)	22	56	22	0
Registry/regulatory boards	5 (7)	20	20	60	0
State research/statistical units	4 (4)	75	0	0	25
TOTAL	150 (183)	24	41	28	7

[a]N refers to the total number of organizations for which information was available for computing the percentages reported. Percentages have been rounded to the nearest whole number.

[b]N in parentheses refers to total number of organizations to which letters were sent.

1. Abstracts of patient or client records.
2. Individualized data on personnel.
3. Budgetary and operational data on programs and/or services.
4. Summary statistics on any of the items stated above.

As shown by Table 7, 24 percent of the executives were willing to provide abstracts of records on patients and clients served by their organizations; 54 percent were unwilling to do so; and 15 percent did not answer the question.

University-related agencies, visiting nurse associations, public social agencies, and hospitals appear more willing to contribute abstracts of records than other types of organizations. Between 34 and 44 percent of these organizations indicated willingness to make abstracts of records available. State research and statistical units, planning agencies, private social agencies, and local health departments were least willing to contribute abstracts of records. Of course, many planning organizations have no individual records on patients and clients. The few that have such records will not relinquish control over access to them by "outsiders."

Table 8 indicates that 34 percent of the executives would be willing to share individualized information on personnel employed by their organizations; 41 percent object to the proposal; and 18 percent did not reply.

TABLE 7

WILLINGNESS TO CONTRIBUTE ABSTRACTS OF RECORDS

Type Organization	N[a]	Response: Positive %	Negative %	No Response/ Neutral %	Non-Applicable %
Hospitals	44 (54)[b]	34	43	23	0
Planning agencies	19 (22)	0	47	32	21
University-related agencies	9 (13)	44	22	11	22
Public social agencies	8 (8)	38	50	0	12
Local welfare depts.	6 (6)	17	83	0	0
Visiting nurse assns.	10 (11)	40	40	10	10
Private social agencies	11 (14)	9	73	18	0
Nursing homes	5 (6)	20	80	0	0
Mental health clinics	20 (24)	25	65	5	5
Local health depts.	9 (14)	11	78	11	0
Registry/regulatory boards	5 (7)	20	60	20	0
State research/statistical units	4 (4)	0	75	0	25
TOTAL	150 (183)	24	54	15	7

[a] N refers to the total number of organizations for which information was available for computing the percentages reported. Percentages have been rounded to the nearest whole number.

[b] N in parentheses refers to total number of organizations to which letters were sent.

TABLE 8

WILLINGNESS TO CONTRIBUTE DATA ON PERSONNEL

Type Organization	N[a]	Response: Positive %	Negative %	No Response/ Neutral %	Non-Applicable %
Hospitals	44 (54)[b]	43	30	27	0
Planning agencies	19 (22)	37	26	16	21
University-related agencies	9 (13)	33	11	33	22
Public social agencies	8 (8)	38	38	12	12
Local welfare depts.	6 (6)	17	83	0	0
Visiting nurse assns.	10 (11)	50	40	0	10
Private social agencies	11 (14)	9	55	36	0
Nursing homes	5 (6)	20	80	0	0
Mental health clinics	20 (24)	35	45	15	5
Local health depts.	9 (14)	11	77	11	0
Registry/regulatory boards	5 (7)	40	40	20	0
State research/statistical units	4 (4)	25	50	0	25
TOTAL	150 (183)	34	41	18	7

[a] N refers to the total number of organizations for which information was available for computing the percentages reported. Percentages have been rounded to the nearest whole number.

[b] N in parentheses refers to total number of organizations to which letters were sent.

Between 40 and 50 percent of state registry and regulatory boards, hospitals, and visiting nurse associations appear willing to contribute individualized data on personnel. Very few private social agencies, local health departments, local welfare departments, and nursing homes would share such information.

As shown by Table 9, 57 percent of the executives would be willing to share budgetary and operational data on their organizations; 23 percent would be unwilling; and 13 percent did not reply. Local welfare departments, nursing homes, private social agencies, and local health departments were least willing to share this kind of information.

Finally, Table 10 indicates that 62 percent of the executives would be willing to provide summary statistics on patients and personnel employed and on budgetary and operational data to a health and welfare information system; 19 percent would be unwilling to cooperate in this way; and 12 percent did not reply. Nursing homes, local health departments, and private social agencies appear least willing to give summary statistics on their operations.

Seven percent of the executives did not respond to these questions about the types of data they could contribute to a community-wide health and welfare information system on the ground that such a system had no applicability to their organizations.

Behind the findings summarized above lie a number of important qualifications and sentiments expressed by respondents to the inquiry. Hospitals usually stated conditional willingness to share

TABLE 9

WILLINGNESS TO CONTRIBUTE BUDGETARY AND OPERATIONAL

DATA ON PROGRAMS AND SERVICES

Type Organization	N[a]	Response			
		Positive %	Negative %	No Response/ Neutral %	Non-Applicable %
Hospitals	44 (54)[b]	68	14	18	0
Planning agencies	19 (22)	63	5	11	21
University-related agencies	9 (13)	44	11	22	22
Public social agencies	8 (8)	75	12	0	12
Local welfare depts.	6 (6)	17	83	0	0
Visiting nurse assns.	10 (11)	50	30	10	10
Private social agencies	11 (14)	27	45	27	0
Nursing homes	5 (6)	20	80	0	0
Mental health clinics	20 (24)	70	15	10	5
Local health depts.	9 (14)	33	56	11	0
Registry/regulatory boards	5 (7)	80	20	0	0
State research/statistical units	4 (4)	75	0	0	25
TOTAL	150 (183)	57	23	13	7

[a] N refers to the total number of organizations for which information was available for computing the percentages reported. Percentages have been rounded to the nearest whole number.

[b] N in parentheses refers to total number of organizations to which letters were sent.

TABLE 10

WILLINGNESS TO CONTRIBUTE SUMMARY STATISTICS

Type Organization	N[a]	Response: Positive %	Negative %	No Response/ Neutral %	Non-Applicable %
Hospitals	44 (54)[b]	70	14	16	0
Planning agencies	19 (22)	63	5	11	21
University-related agencies	9 (13)	44	11	22	22
Public social agencies	8 (8)	75	12	0	12
Local welfare depts.	6 (6)	83	17	0	0
Visiting nurse assns.	10 (11)	60	20	10	10
Private social agencies	11 (14)	36	36	27	0
Nursing homes	5 (6)	0	80	20	0
Mental health clinics	20 (24)	70	15	10	5
Local health depts.	9 (14)	33	56	11	0
Registry/regulatory boards	5 (7)	100	0	0	0
State research/statistical units	4 (4)	75	0	0	25
TOTAL	150 (183)	62	19	12	7

[a] N refers to the total number of organizations for which information was available for computing the percentages reported. Percentages have been rounded to the nearest whole number.

[b] N in parentheses refers to total number of organizations to which letters were sent.

information--subject to approval by boards of trustees and resolution of the issues of confidentiality and medical ethics involved. Abstracts of records which identified patients by name were not likely to be released without explicit patient authorization.

Two planning agencies strongly recommended design of a system incorporating summary statistics regarding patients and clients, manpower, and budgetary and operational data on programs and services.

Local welfare departments were reluctant to commit themselves in any way. They wished to refer the decision to the Massachusetts Department of Public Welfare, under whose authority they now fell. Two of these departments, however, offered the opinion that confidentiality was likely to be an obstacle to sharing information on individual welfare clients and personnel. Similarly, local health departments were opposed to sharing information on individual patients because of the confidential nature of such information.

Registry and regulatory boards did not have data on patients or clients. However, with the permission of the governor, they would share all other types of data.

In effect, not many organizations are willing to make unqualified commitments to contribute data to a community-wide health and welfare information system. This is not surprising considering the feelings of many executives about the awesomeness of the responsibility they have for safeguarding the interests of

the populations they serve. The argument that a community-wide information system will help improve health and welfare services to the community and, therefore, that organizations and their clients have more to gain than to lose from data sharing is not overwhelmingly convincing.

Executives, suspicious of the intent and outcome of centralization of information on individuals, might argue as one did:

> Personally, I am strongly opposed to any centralization of information about individual patients. The confidentiality would be certain to be jeopardized and the personal aspects of medical/psychiatric care would be short-circuited. With 1984 only sixteen actual years away, I am tempted to say that if such a system were inaugurated, I would be inclined to either resign or in a more clandestine way block the so-called efficiency of such an organization at every possible opportunity.

Although perhaps less alarmed than this one executive, the majority of executives surveyed anticipate considerable difficulty in sharing information which identifies individual patients and clients and, to a degree, individual employees.

Few executives take exception to release of summary statistics of various kinds, nor do they often object to making known budgetary and operational data on programs and services--although even here clearance by a board of trustees or its equivalent usually is necessary before such release.

In sum, the positions taken by executives do not exceed the bounds of current organizational policies, nor do they promise to ease existing restrictions on access to information.

Summary and Conclusions

Analysis of the 150 replies to letters sent to 183 executives of health organizations and related agencies in Metropolitan Boston gives indication of executive reaction to proposals for developing a computer-based health and welfare information system to serve the area.

Almost three-quarters of the executives are favorably disposed toward the concept of a community-wide health and welfare information system. They recognize the need for more adequate information to assist them in planning and research. Consequently, the concept has basic appeal. In addition, they are willing to participate in or cooperate with a system--but always within constraints imposed by law, organizational policy, finances, and manpower. These constraints are often expressed as doubts or fears about a system which pools data on patients and clients and on the organizations and personnel which serve them.

Questions about confidentiality are universal. How are the rights of individuals to privacy concerning their problems, needs, and desires to be preserved? Who would have access to information about individuals and under what conditions? Mental health clinics are particularly anxious about the latter issue. One prominent Catholic clergyman was of the opinion that few clients of his private social agency would give permission to have identifying information made available to outside sources. He went on to attack on moral grounds "one further step in the direction of having all

facts about all persons available in one central place for the elite to use for purposes that they deem to be noble." In his opinion, the key to protection of the natural rights of individuals to privacy was their explicit consent to the release of information about them.

Specific statutes forbidding release of abstracts of patient or client records and of data on personnel were cited in two instances.[3]

Almost 30 percent of the executives prefer a community-wide health and welfare information system under voluntary auspices. With the exception of executives of organizations already under state or Federal control, most executives are of the opinion that governmental control and red tape would ruin any system. On the other hand, four executives who favored Federal auspices did so mainly because they felt that Federal government alone can adequately fund a system and follow through to completion. State control is preferred by executives of state agencies.

Executives hold varied opinions about what form a community-wide health and welfare information system should assume. Cumulatively, fewer doubts and fears have been expressed about a directory of information than about any other form of a system.

The positions taken with respect to the types of data which could be contributed to a system are largely consistent with

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[3]The statutes cited were: Massachusetts General Laws, Chap. 151 A and Chap. 602, sec. 84.

opinions about preferred form. The majority anticipate considerable difficulty with a system which identifies individual patients and clients and, to a degree, which identifies employees. Few take exception to release of summary statistics of various kinds; nor do they object to making known budgetary and operational data on programs and services.

It is clear that while there is no strong positive preference for an information system which takes the form of a directory of information stored in various agencies, the preponderant unwillingness to provide abstracts of records on patients and clients--or to provide individualized data on personnel--narrows the feasible choice to a directory form of an information system. Another non-threatening type of system would be a mechanism for consolidating summary statistics gathered from every conceivable source.

An archival system, containing abstracts without names or social security numbers, is another possibility. Blue Cross and United Community Services are developing systems of this kind. Geographic-based record linkage of information gathered by these and other such systems holds promise.

Still another type of system suggested by several executives is a computer-updated inventory of health and welfare resources in Metropolitan Boston.

As systems designers consider ways to fashion formal linkages between developing information subsystems in Metropolitan Boston, they will undoubtedly gravitate toward establishing a superordinate

organization to guide and coordinate efforts. One of the primary issues for deliberation will be the kind of concrete service and/or information system this organization should develop in order to get started and to win support.

Certainly, a comprehensive archival computer-based information system capable of linking records from every conceivable source will have the greatest appeal technologically. In face of undoubted opposition to so powerful a system, it might seem strategic to begin with a "start-up" system built around a directory of information stored in various agencies and to expand later.

The findings of this chapter give cause for doubt about the wisdom of such a strategy. If executives are asked now to contribute data which identify individuals by name or social security number, few will join the system. If, on the other hand, a system is set up without such identifying information and there are attempts later to change over to a more powerful type of system, a massive educational campaign is likely to be necessary to allay entrenched negative feelings and to prevent widespread defection from the system.

Indeed, any system starting weak in order to gain a "foot in the door" might from the very outset draw animosity toward itself.

CHAPTER IV

COMPATIBILITY OF INFORMATION IN DATA COLLECTION FORMS

Introduction

It will not do to allow enthusiasm for new computer capabilities to seduce one into sweeping up "every imaginable kind of data in a vast omnium-gatherum."[1] At the same time, it would be impractical to ignore existing files of data in developing a health and welfare information system for Metropolitan Boston. Such files, after all, reflect value judgments and decisions about which items of information are needed to assist organizations to function.

Urging that urban management information systems be built upon certain basic, although imperfect, files of data which already exist in most metropolitan areas, Edward F.R. Hearle, director of public administration services of the management consulting firm of Booz, Allen and Hamilton, Inc., cites the following reasons:

> Given that urban areas are diverse, users dissimilar, and that we don't know exactly what data are absolutely required for anything except certain legal functions (like assessing where they often are spelled in law), an incremental approach to urban information systems makes considerable sense. This means

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[1] Angus Campbell, "Some Questions About the New Jerusalem" (paper delivered at the Fourth Annual Conference of the Council of Social Science Data Archives, University of California, Los Angeles, June 14-17, 1967), pp. 1-2.

> starting with a file of data about given areal units--or persons--that serve a feasible range of operating needs and gradually expanding this file (and modifying or partitioning it) based on the needs of existing and added users. I do not believe it would be feasible to design, implement, and sustain an "urban management information system" in a one-shot turn-key operation. The requirements for such a system, and thus its precisely perceived payoffs, are insufficiently clear, at least in 1967.[2]

This chapter presents data on the degree to which information presently seen as needed by selected health and welfare agencies is compatible in form and definition. The analysis of forms now used, from the standpoint of compatibility of item definitions or coding schemes, has a bearing on the choice of relevant items of information for inclusion in a health and welfare information system. If a system serving Metropolitan Boston is to be built upon existing files of data because these data are needed by organizations for day-to-day functioning or for discharging statutory obligations (e.g., processing and reporting of health and vital statistics for the Commonwealth by the State Department of Public Health), the degree to which information collected by various agencies is compatible becomes a vital consideration. Incompatible definitions or coding schemes interfere with the development of valid and reliable measures of qualities and attributes of people, organizations, and geographic areas in the following ways:

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[2]Edward F.R. Hearle, "Urban Management Information Systems" (paper presented at the Symposium on Application of Computers to the Problems of Urban Society, sponsored by the Association for Computing Machinery, New York, Nov. 10, 1967), p. 13.

1. The same label or name may be used to refer to entirely different qualities (e.g., "employment" may be used to refer to "job title" or "occupation" or "whether or not employed").

2. Different classifications of the same quality (e.g., "race" classified either as "Caucasian, Negro, Puerto Rican, Oriental, Other" or as "white, non-white") may impede comparison of data gathered from various sources measuring that quality.

3. Different classifications of the same quality or attribute may prevent flexible aggregation and merging of files of data gathered from various sources measuring that quality.[3]

Unless a modicum of compatibility exists or can be created by modification of existing files of data on people, organizations, and geographic areas, even Hearle's concept of building on the information that organizations already have may be untenable. Basically, incompatibility which cannot be brought under control by standardization will compromise from the outset any health and welfare information system relying on existing data. Incompatible

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[3]This is likely to happen because different classification schemes tend to reduce precision by forcing collapse of unequal categories in order to achieve a common base--often to the destruction of original intent and meaning. For example, annual family income grouped by one agency as "under $1,000-$1,999, $2,000-$2,999, $3,000-$3,999" and by another agency as "under $1,500-$2,499, $2,500-$3,499, $3,500-$4,999" would make it impossible for an analyst to merge and aggregate these data to determine the proportion of persons served by these two agencies who are under the "poverty line" (having annual family incomes of less than $3,000). In desperation, the analyst might attempt to solve the problem by making assumptions about the proportion of persons having a family income of less than $3,000. Such a procedure--even assisted by reference to a table of

sets of data will so impair the usefulness of a system that people and organizations controlling access to needed information may refuse to release data for this very reason. Unless a health and welfare information system can demonstrate that it has overcome the hurdle of incompatible data, there is no rational reason why anybody should support it financially or politically.

For these reasons, then, the present analysis will not only disclose incompatibility in definitions and coding schemes among agencies but will also recommend the changes necessary to achieve compatibility. It is debatable, however, whether affected agencies will agree to accept any recommended changes. In some instances, these recommendations would entail considerable reorientation of current practices.

Procedures and Definitions

One hundred fourteen forms used in or associated with the nine information systems selected for in-depth study in this report were coded and analyzed to determine: (1) the extent to which forms ostensibly seeking the same information use compatible definitions;

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random numbers--introduces an unknown amount of error into the data. This error is compounded when measures of covariation are applied to the data insofar as quite incompatible quantities may be paired. At best, the analyst must look for a common bound (e.g., $10,000 per year) in the two sets of family income data and then must collapse all lesser intervals in both sets of data into one inclusive category--"$10,000 or less"--which is meaningless if the analyst's original intent was to determine the proportion of persons having annual family incomes of less than $3,000.

(2) the possibilities which exist for individual- and geographic-based record linkage; and (3) the degree of redundancy in data-gathering efforts.

The nine information systems analyzed in depth were: (1) the outpatient and emergency clinic record system of the New England Medical Center Hospitals, (2) the computerized outpatient and emergency clinic information system of the Children's Hospital Medical Center, (3) the computerized management information system of Associated Catholic Hospitals, Inc., (4) the morbidity data collection system of the Boston Department of Health and Hospitals, (5) the health and vital statistics system of the Massachusetts Department of Public Health, (6) the morbidity data collection system of the Massachusetts Department of Public Health, (7) the medical assistance information system of the Massachusetts Department of Public Welfare, (8) the utilization review and provider service system of Massachusetts Blue Cross and Blue Shield, and (9) the budgetary and service statistics collection system of United Community Services of Metropolitan Boston.

Efforts to determine how much redundancy there is in the gathering of information were not productive. It quickly became apparent that the notion of redundancy was extremely relative within the context of the nine information systems studied. No form asked for the same item of information twice. On the other hand, various forms within the same organization sought the same items of information.

If redundancy is judged from the perspective of a real-time, on-line computerized information system (in which a composite record of all transactions involving a specific individual can be stored in magnetic memory for instant recall), all the noncomputerized systems were redundant. But from the standpoint of nonautomated information systems, redundancy was absolutely necessary to insure that enough information was procured to provide immediate service and to permit reference to and filing of additional information in the patients' master records. In view of these circumstances, redundancy does not appear to be an important issue--unless the efficiencies possible through a real-time, on-line system are accepted as the norm.[4] Acceptance of such a norm does not seem warranted at this time. Perhaps in the future, when use of real-time, on-line computers has become economical and pervasive in American society, such a norm can be accepted.

Each of the 114 forms was coded along 38 dimensions.[5] The dimensions were: (1) organization using the form, (2) type of form, (3) date of last revision, (4) title or subject of form, (5) geographic areas of jurisdiction or service, (6) mode of defining address, (7) whether flexible matching and linkage of individual records to geographic areas, based on exact address

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[4]Of course, a certain minimum amount of information must be obtained each time from a given patient and keyed into even a real-time, on-line system in order to gain access to the patient's composite record.

[5]See Appendix C for copy of coding conventions.

coding, was possible, (8) whether name of individual, institution, program, or geographic area to which the form referred was requested, (9) whether telephone number of individual, institution, or program was requested, (10) whether date of application, admission, discharge, visit, report, or program period was requested, (11) whether name of next of kin or person responsible for patient was requested, (12) whether name of spouse or parent was requested, (13) whether address and/or phone number of next of kin or person responsible for patient was requested, (14) whether social security number was requested, (15) whether a serial, index, case, patient, or other type of intra-organizational reference number was requested, (16) whether Blue Cross identification number was specifically requested, (17) whether name of person completing the form was requested, (18) whether position of person completing the form was requested, (19) whether weight was requested, (20) whether height was requested, (21) mode of defining diagnosis, (22) whether type of treatment prescribed or given was requested, (23) whether tests, cultures, or drug prescriptions were requested, (24) whether notation of previous visits to same unit of organization was requested, (25) whether criminal record was requested, (26) whether record of previous hospitalization or other involvement with health or social agencies was requested, (27) whether charges for services rendered were requested, (28) mode of defining health insurance coverage, (29) mode of defining age, (30) mode of defining birthplace, (31) mode of defining sex, (32) mode of

defining race, (33) mode of defining marital status, (34) mode of defining religion, (35) mode of defining education, (36) mode of defining occupation and/or employment, (37) mode of defining draft or military service status, (38) whether individual record matching and linkage based on name, exact birth date, and birthplace or on a universal identification number (social security number) was possible.

Coding the 114 forms along the 38 dimensions was, for the most part, uncomplicated. The title or subject matter of the forms was apparent by inspection. Similarly, the forms were easily grouped by type. However, when some forms of a specific title or subject matter requested an item of information which others of the same title or subject matter did not request, the question of applicability arose. What rule should be adopted for deciding when an item of information is applicable to a form? Obviously, there is room for wide divergence of opinion, depending upon the frame of reference adopted. Instead of attempting to superimpose judgments or to second-guess the intent and purpose of the original designers of the forms, the following decision-rule was adopted: <u>If more than one form of a specific title or subject matter requested an item of information, that item was considered appropriate for every form of that title or subject matter</u>. This decision-rule is inclusive; any number of more exclusive rules might have been adopted. An inclusive rule retaining as many items as possible seemed appropriate because it would not prematurely exclude from consideration

information potentially useful for a community-wide health and welfare information system.

Codes describing variations in the way forms requested items of information were empirically derived. Each item of the same type was studied on the forms in which it appeared and codes assigned to describe the variation. An open-ended request was always distinguished from a close-ended request for information.[6]

Codes describing the possibilities for individual- and geographic-based record linkage were assigned by computer program, using codes describing other items of information requested by the forms.[7] If a form referred to an individual and requested the name, exact birth date (year, month, and day), and city and state of birth, or if it requested the individual's social security number, individual record linkage was considered possible.[8] If a form referred to an individual and requested the exact address and city or town of residence,

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[6]An open-ended request was defined as one which did not specify a choice of alternatives or some universal code such as the International Code of Diseases, Adapted. A close-ended request was defined as one which did so specify.

[7]Reference to the coding conventions in Appendix C, therefore, will not disclose codes indicating the possibilities for individual- and geographic-based record linkage.

[8]See E.D. Acheson, Medical Record Linkage (London: Oxford University Press, 1967), ch. 3, for a thorough discussion of the advantages and liabilities associated with various methods of record linkage. A number of studies find that use of name, date of birth, and place of birth yield correct record matching in about five-sixths of the pairs of records. One or more major inconsistencies occur in the remaining one-sixth of the record pairs. (Acheson, pp. 66-67.) Use of social security numbers to link individual records is presumed to yield a higher proportion of correct matches.

flexible geographic-based record linkage was considered possible.[9]

The analyses which follow do not permit inference concerning the degree to which information requested by the forms under study is actually presented in the files of organizations using them. Nor do they permit inference concerning the reliability of the information actually present in the files.[10]

Information coded from the 114 forms was punched on cards and analyzed. Frequency distributions calculated for 35 items of information requested by the various forms show the variability or degree of compatibility of definitions. Cross-tabulations indicate

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[9]The DIME file developed by the staff of the New Haven Census Use Study uses exact address coding to achieve record-to-address linkage. In essence, the Dual Independent Map Encoding system employs a geographic base file which relates street addresses to geographic x, y coordinates. The file employs redundant encoding of map features so that errors can be detected by computer edits. The file makes it possible to aggregate flexibility data associated with specific street addresses over areas of various sizes by simply defining the boundaries of the respective areas. Such aggregation permits avoidance of disclosure of confidential information. (See Donald F. Cooke and William H. Maxfield, "The Development of a Geographic Base File and Its Uses for Mapping" [Paper presented September 9, 1967, at the annual conference of the Urban and Regional Information Systems Association, Garden City, Long Island, New York.])

[10]Obtaining answers to these questions was not within the scope of work of the contract between The Medical Foundation, Inc., and the Joint Center for Urban Studies of MIT and Harvard University. Studies to obtain answers to these questions are likely to be expensive. They would entail (1) sampling records to determine item by item the frequency with which missing data occur and (2) sampling and re-interviewing patients or comparing their records from different sources to determine the frequency with which inconsistent data occur. (See, for example, Center for Vital and Health Statistics, "The Comparability of Age on Death Certificates and Matching Census Records" [Washington, D.C.: U.S. Public Health Service, Department of Health, Education, and Welfare,

item by item the degree of compatibility of definition by type of form.[11]

Origins and Types of Forms Studied

Of the 114 forms analyzed, 34 (30%) were obtained from Associated Catholic Hospitals, eight (7%) from Massachusetts Blue Cross-Blue Shield, 16 (14%) from the Boston Department of Health and Hospitals, 12 (11%) from Children's Hospital Medical Center, 11 (10%) from New England Medical Center Hospitals, 11 (10%) from the Massachusetts Department of Public Welfare, 12 (11%) from United Community Services of Metropolitan Boston, and 10 (9%) from the Massachusetts Department of Public Health (four from the Division of Communicable and Venereal Diseases and six from the Division of Health and Vital Statistics).[12]

June 1968 .) These questions bear directly on the critical issue of whether attributes of people, organizations, and geographic areas, chosen for inclusion in a health and welfare information system, can be reduced to measures which are sufficiently reliable and valid to attain the objectives of the system.

[11] Cross-tabulations by organization were also made. However, the results of this analysis are not presented in this report in order to avoid disclosures which might embarrass any of the organizations studied. The data presented herein suffice to answer the questions about compatibility of definitions and the possibilities of individual- and geographic-based record linkage. If executives of any of the nine information systems studied in depth wish to obtain frequency distributions for their own organizations, these will be supplied upon request.

[12] All percentages in this and succeeding sections have been rounded to the nearest whole number. Cumulatively, they will not necessarily add to 100%.

With respect to type, 10 (9%) were admission, registration, or discharge forms; four (4%), reimbursement application forms; two (2%), reimbursement authorization forms; five (4%), medical, epidemiological, or case record forms; 23 (20%), forms for requesting and recording results of laboratory tests and other diagnostic procedures; seven (6%), morbidity reporting forms; eight (7%), health or social status report forms (e.g., immunization, birth, death, or marriage); 13 (11%), budgetary or financial report forms; 19 (17%), summary report forms for compiling service statistics; six (5%), billing forms; one, blood bank credit form; and 16 (14%), other miscellaneous forms.

Two-thirds of the forms analyzed specified the year in which the form had last been revised. Three were last revised before 1960; the remaining 74 for which information was available, after 1960. Sixty-three had been revised during the last three years (1966-68).

Geographic Area of Jurisdiction or Service

The geographic area of jurisdiction or service of each form was, within broad limits, ascertainable. In only three instances was it not possible to determine the relation between the form and its geographic area of jurisdiction or service. For the rest, almost two-thirds referred to characteristics of organizations or to the populations they served--from whatever quarter they came. Slightly less than one-third of the forms analyzed were judged to

refer to Massachusetts residents only. One form offered close-ended alternatives with reference to the geographic area of jurisdiction. Clearly, forms used to collect health and welfare data do not provide exact delineation of geographic jurisdictions. In some instances, however, reference to the addresses of the patients or clients served may provide more precise information. The degree to which such reference permits more precise determination of geographic areas of jurisdiction or service is treated below.

Some types of forms, more than others, referred to Massachusetts residents only. All eight health and social status report forms, six of seven morbidity reporting forms, and three of four reimbursement application forms applied to Massachusetts residents only. Only a small fraction of admission, registration, or discharge forms, of medical, epidemiological, or case record forms, and of budgetary and financial report forms referred to Massachusetts residents only. None of the remaining types of forms made such reference.

Address- and Geographic-based Record Linkage

Of the 114 forms, 21 (18%) requested full address (street, city or town, and state); 25 (22%) made open-ended requests for address; seven (6%) asked for city only; one sought state only; and nine (8%) requested address in some other fashion. Forty-three forms (38%) made no provision for address, and for eight forms (7%) address coding was not applicable.

Where applicable, the manner in which address was requested varied by type of form. Of 10 admission, registration, or discharge forms, three requested full address, six made an open-ended request, and one did not ask for it. All four applications for reimbursement sought full address. One of the two reimbursement authorization forms requested full address, and the other asked for state of residence only. Two of five medical, epidemiological, or case record forms required full address; the other three did not ask for it. Only one of the forms requesting and recording results of laboratory tests or other diagnostic procedures made provision for recording address. Five of seven morbidity reporting forms made an open-ended request for address; the other two asked for it in other terms.

Of eight health and social status reports, five requested full address, two made open-ended requests, and one did not ask for it. Of 13 budgetary and financial report forms, six made open-ended requests, two sought city only, and five did not ask for address. Of 11 summary report forms, three sought full address, two made open-ended requests, two asked for city only, one requested address in other terms, and three did not ask for it. Neither billing nor blood bank credit forms requested address. Of 16 other miscellaneous forms, three sought full address, three sought city only, and three made an open-ended request. Six asked for address in other terms, and one made no request.

Obviously, the manner in which forms of most types seek address information is extremely variable. Open-ended requests are an additional source of variability. They may yield address information ranging from full street, city or town, and state, to city or state only, to address in other terms (e.g., name of institutional residence). Under these circumstances, special studies to determine geographic areas of jurisdiction or service are likely to prove difficult unless access to records containing the full address is obtained.

The prospect of using exact address codes to link existing records of every type flexibly to geographic areas seems remote if dependent upon records in isolation. Of 106 forms for which address coding was applicable, only 21 (20%) permitted such linkage. Depending upon the consistency with which open-ended requests for address yield full address, the percentage of forms permitting flexible geographic-based record linkage might approach 40 percent as an upper limit. Of course, to the extent that partial records are filed in one place by reference to an intra-organizational serial number and the full address appears somewhere in the composite record, the possibility of geographic-based record linkage improved considerably. Many organizations maintain such a system. Searching and abstracting needed information from the composite record and obtaining adequate personnel and resources to pay for this become the real issues after health and welfare executives have decided to undertake the task.

Name, Telephone Number, and Date of Transaction

Virtually every form asked for the name of the individual, institution, and program. In one instance, the name of the geographic area to which a form referred was requested.

Of 114 forms, a request for the telephone number was judged appropriate for 69 forms (41%). Of the 69 forms, 15 (22%) requested the telephone number; 54 (78%) did not ask for it.

Date of transaction (whether application, admission, discharge, visit, report, or program period) was considered appropriate for 100 forms (88%). Of the 100 forms, 89 percent requested the date of transaction; 11 percent did not seek it.

Identification Numbers: Intra-organizational, Social Security, and Blue Cross

Seventy-five of the 114 forms (66%) made provision for an intra-organizational reference or identification number; thirteen forms (11%) made no provision; and such a number was judged inappropriate for 26 forms (22%). No provision was made, where applicable, for an intra-organizational identification number by one out of eight admission, registration, and discharge forms; two out of five medical, epidemiological, and case record forms; five out of six morbidity reporting forms; two out of nine summary report forms; and three out of 14 other miscellaneous forms.

The social security number was judged inappropriate for 62 (56%) of the forms analyzed. Of the remaining 50 forms for which it was judged appropriate, 39 forms (78%) make no provision for

obtaining it. Clearly, the social security number is not considered an important or relevant piece of information by many forms designers in the fields of health and welfare. This conclusion takes into account and eliminates forms which do not refer to individuals. It is striking that so many forms of the same title or subject matter referring to individuals were excluded when the study applied the rule it had adopted for deciding when an item of information was appropriate for a form of a specific title or subject matter (appropriate if present on more than one form). The significance of these findings will be discussed below within the context of individual record matching and linkage.

Eleven forms specifically requested the Blue Cross identification number. Six were admission, registration, and discharge forms; two were summary report forms; the remainder consisted of one reimbursement application form, one reimbursement authorization form, and one other miscellaneous form.

Name, Address, and Telephone Number of Next of Kin, Spouse, Parent, or Other Responsible Person

A request for the name of the next of kin, spouse, parent, or other responsible person was judged appropriate for 31 (27%) of the 114 forms analyzed. Of the 31 forms for which it was considered applicable, 17 forms (55%) asked for the name, while 10 forms (45%) did not request it. Of the various types of forms, only health and social status report forms and admission, registration, and discharge forms consistently requested the name of a relative or other responsible person.

A request for the address and telephone number of the next of kin or other responsible person was judged appropriate for 25 (22%) of the 114 forms analyzed. Of the 25 forms for which it was considered applicable, eight (32%) requested both address and telephone number, while 12 (48%) asked for address only. Five other forms (20%) sought neither address nor telephone number of the next of kin or other responsible person.

Name and Position of Person Completing Form

Provision for the name of the person completing the form was considered appropriate for 109 forms (95%). Of the 109 forms, 84 (77%) asked for the name, while 25 (23%) did not seek it. The majority of the various types of forms requested that the person completing the form provide his name. Summary report forms were the exception. Eleven (61%) of 18 such forms made no provision.

A request for the position of the person completing the form was considered appropriate for 97 (85%) of the 114 forms analyzed. Of the 97 forms, 68 (70%) requested the position, while 29 (30%) did not ask for it. Of the various types of forms, only summary report forms and billing forms consistently failed to ask for the position of the person filling them out.

Patient Height and Weight

Only two forms actually required the height and weight of the person to whom the form referred. One was a registration form; the other was a form for requesting and recording results of laboratory

tests and other diagnostic procedures. Ignoring the study's decision-rule for declaring an item of information appropriate (because height and weight are among the important actuarial indices of life expectancy), six other forms were judged deficient because they did not require the height and weight of the person to whom they referred. They consisted of three medical record forms, two registration forms, and one other miscellaneous form.

Diagnosis, Treatment, Tests, and Procedures

The request for diagnosis was judged appropriate for 41 (36%) of the forms analyzed. Of the 41 forms, 30 (73%) made an open-ended request; two asked for the International Code of Diseases, Adapted; eight (20%) offered a close-ended coding scheme other than the ICDA; and one form did not request diagnosis. Diagnosis was requested by one or more forms of every type except budgetary and financial report forms, billing forms, and the solitary blood credit report form. The two forms seeking diagnosis according to the ICDA were both medical record forms.

Information about prescribed treatment was considered appropriate for 20 (17%) of the 114 forms analyzed. Of the 20 forms, 15 forms (75%) requested information about prescribed treatment; five others made no such provision. Three out of five medical, epidemiological, and case record forms and two out of five morbidity reporting forms asked for prescribed treatment. Similarly, all three summary report forms and all six miscellaneous other forms for which it was

considered appropriate made provision for obtaining information about prescribed treatment.

Information about tests, cultures, and prescribed medicines was judged appropriate for 38 (33%) of the 114 forms analyzed. Of the 38, 33 forms (87%) requested such information; five others made no provision for obtaining it. Among the various types of forms, those typically requesting information about tests, cultures, and prescribed medicines were medical, epidemiological, and case record forms, forms for requesting and recording results of laboratory tests and other diagnostic procedures, morbidity reporting forms, and a few miscellaneous other forms for which such information was judged applicable.

Previous History of Hospitalization, Visits to Same Clinic or Other Unit of an Organization, and Criminal Record

Previous history of hospitalization or other involvement with health and social agencies was judged appropriate for 21 (18%) of the forms analyzed. Of the 21 forms, 18 (85%) requested such information, while three did not. Of the various types of forms, only admission, registration, and discharge forms sought this information to any great extent. Eight of 10 such forms asked for previous history of hospitalization or involvement with health and social agencies.

A request for information about previous visits to the same clinic or other unit of the organization providing service was

considered appropriate for 12 forms. Nine of the 12 forms actually requested such information; the other three did not. Only one of the 114 forms analyzed--a morbidity reporting form--raised the issue of a previous criminal record.

Charges and Health Insurance Coverage

A listing of charges was judged appropriate for 43 (38%) of the forms analyzed. Of the 43, 40 forms (93%) were designed to list charges for services rendered. Reimbursement, application, and authorization forms, forms for requesting and recording results of laboratory tests and other diagnostic procedures, budgetary and financial report forms, summary report forms, and, of course, billing forms typically listed charges.

Of 114 forms analyzed, a request for information about health insurance coverage was considered appropriate for 48 (42%). Thirty-four (71%) of the 48 forms did not request the information. Of the 14 forms which did ask about health insurance coverage, half made open-ended requests; the other half offered a close-ended choice of alternatives. In addition, 11 of the 14 forms specifically requested the Blue Cross identification number, if applicable.

Age

Eighty-two (72%) of 114 forms could appropriately have requested the age of the person to whom the forms referred. Of this number, 12 (15%) requested the exact year, month, and day of birth; 50 (61%) sought age as of the last birth date; seven (9%) made an

open-ended request; three asked for the year and month of birth; one offered a choice of alternative age groupings; and nine (11%) did not ask for age at all.

Characteristically, reimbursement application forms and health and social status reports asked for the exact year, month, and day of birth. Approximately the same number of application, registration, and discharge forms sought the exact birth date as requested age at last birth date. The majority of medical, epidemiological, and case record forms, forms for requesting and recording results of laboratory tests and other diagnostic procedures, morbidity reporting forms, billing forms, and other miscellaneous forms asked for age at last birth date.

Birthplace

A request for birthplace was considered appropriate for 36 (32%) of the forms analyzed. Of the 36 forms, 13 (36%) made an open-ended request; two offered a choice of alternatives; and 18 (50%) did not seek information about birthplace. One form requested the city and state of birth; one sought the country of birth only; and another asked for birthplace in other terms. Budgetary and financial report forms and billing forms never asked for birthplace.

Sex

Sex, although a topic of considerable interest and a source of complication in human affairs, in the present context caused no difficulties whatsoever. It was judged an appropriate issue for

consideration by 79 (69%) of the forms analyzed. Of the 79 forms where sex was an appropriate consideration, 65 forms (82%) requested information on the subject; 14 forms (18%) did not ask for it. There was no variation in the way it was defined.

Marital Status

Marital status was considered an appropriate item of information for 37 (32%) of the 114 forms analyzed. Of the 37 forms, eight (22%) made an open-ended request; 13 (35%) offered a choice among alternatives; three asked for marital status in other terms; and 13 (35%) did not seek this information. Again, there was no characteristic mode of definition under which marital status was requested which distinguished one type of form from another.

Race

Thirty-five (31%) of the forms analyzed could appropriately have asked for the race of the person to whom the form referred. Of the 35 forms, 10 (29%) made an open-ended request; six (17%) asked whether the person was "white or other"; three asked whether the person was "white, Negro, or other"; one provided an extensive check-list; five (14%) requested information in other terms; and 10 (29%) did not ask for information about race. There was no characteristic mode of definition under which race was requested which distinguished one type of form from another.

Religion

A request for information about religion was judged appropriate for 30 (26%) of the forms analyzed. In view of the sociological importance of religion as an explanatory variable, the study's decision-rule for judging the appropriateness of items of information for inclusion in forms of specific title or subject matter was suspended. This meant that three medical, epidemiological, and case records, three morbidity reporting forms, and six health and social status report forms were added to the group of forms for which information about religion was considered appropriate.

Of the 30 forms for which religion was an appropriate consideration, five made an open-ended request; three offered a choice among alternatives; two asked for religion, church, and name of clergyman; and 20 (67%) did not seek information about religion at all. Most notable for their failure to ask for religion were the forms which were brought into consideration by suspension of the decision-rule mentioned above. From the standpoint of epidemiology and the study of social functioning, it would appear blind for medical, epidemiological, and case records, for morbidity reporting forms, and for health and social status reports to neglect inquiry about religion. Sociocultural differences in susceptibility and reaction to disease and to the use of health facilities are too well known to be ignored.

Education

Only two of the 114 forms requested information about education. One form asked for the last grade completed; the other

made an open-ended request. As with religion, the importance, sociologically, of education as an explanatory variable cannot be understated. Certainly somewhere in the patient or client record there should be reference to educational attainment.

Occupation and/or Employment

Twenty-four (10%) of the 114 forms analyzed could appropriately have requested information about occupation and/or employment. Again, the decision-rule governing judgment about the appropriateness of including information on forms was suspended to include three medical record, epidemiological, and case record forms. Of the 24 forms for which information about occupation and/or employment was considered appropriate, four made an open-ended request; eight requested the name of the employer; five asked for information about occupation in other terms; and seven did not seek any information in this regard. Application, registration, and discharge forms tended to ask for the name of the employer; otherwise, there was no pattern in the way various types of forms sought information about occupation and/or employment.

Draft or Military Service Status

Only three of the 114 forms analyzed requested information about draft or military service status. All three forms simply asked whether the person to whom the form referred was a veteran.

Individual Record Matching and Linkage

Linkage of records referring to individuals, based upon name, exact birth date, and city and state of birth (or the individual's social security number), appears an even more remote possibility than geographic-based record linkage. Of 101 forms referring to individuals, only 11 gave sufficient information for individual record matching and linkage. What is more, the 11 forms could be matched and linked because they made provision for obtaining the social security number--not because they supplied name, exact birth date, and city and state of birth. The recent uproar in Congress over the proposal to use social security numbers to link, in a national data center, records of United States citizens (records now scattered throughout bureaucrasies of the Federal government) does not permit optimism about procuring increased use of the social security number for linkage purposes on health and related records. Health and welfare administrators are likely to have been sensitized to the political dangers inherent in such a course.

Fact Finding for Comprehensive Health Planning in Massachusetts

Insufficient knowledge about the representativeness of the 114 forms derived from the nine information systems selected for in-depth study is the major shortcoming of the analysis and findings just presented. The suspicion always lurks that study of another sample of forms derived from nine other information systems selected

by the same or different criteria might yield contradictory findings.

Fortunately, replication and conformation of the present findings is possible by reference to the findings of a study of 139 record forms now used by various divisions of the Massachusetts Department of Public Health. Under a U.S. Public Health Service grant, the Massachusetts Department of Public Health has been conducting a study entitled "Fact Finding for Comprehensive Health Planning in Massachusetts."[13] To date, 13 divisions of the Department have been surveyed to learn what information is currently collected, what record forms are used, and how the information gathered is processed and analyzed. The 13 divisions surveyed were: (1) Adult Health, (2) Alcoholism, (3) Communicable and Venereal Diseases, (4) Dental Health, (5) Food and Drugs, (6) Health and Vital Statistics, (7) Hospital Facilities, (8) Local Health Services, (9) Maternal and Child Health Services, (10) Nursing Homes and Related Facilities, (11) Nursing Section, (12) Sanatoria and Tuberculosis Control, and (13) Lemuel Shattuck Hospital.[14]

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[13]Mrs. Elizabeth K. Caso, M.S. in Hygiene and director of the Department's Community Services, is project director. Miss Phyllis Hearst, M.S. in S.S. and coordinator of Community Services, has been responsible for the part of the project which deals with service records of the various divisions of the Massachusetts Department of Public Health. The Medical Foundation, Inc., wishes to express gratitude to Dr. Alfred L. Frechette, commissioner, and to Mrs. Caso and Miss Hearst for permission to cite and to use preliminary findings of their study in this report.

[14]A degree of overlap exists between the Massachusetts Department of Public Health study and this study insofar as both have

Preliminary findings from "Fact Finding for Comprehensive Health Planning in Massachusetts" are presented in the paragraphs which follow.

One hundred thirty-nine record forms are employed in 13 divisions of the Massachusetts Department of Public Health, eight or 10 of which are used for accumulation and transfer purposes. Strictly speaking, these latter forms do not fall within the same class as the rest--which are primary data collection forms.

Of 139 forms, 75 (54%) refer to individual patients; 10 (7%) to communities; four (3%) to hospitals and sanatoria; six (4%) to clinics; three (2%) to nursing homes, rest homes, and extended care facilities; nine (6%) to day care centers and schools; 16 (11%) to programs; 13 (9%) to business establishments; one to manpower; and one to home health agencies.

Thirteen basic types of record forms were identified. The 139 forms are distributed over the 13 types as follows: six (4%) applications for admission or registration; one application for license; 10 (7%) applications for reimbursement; one authorization for reimbursement; 20 (14%) medical, epidemiological, or case records; 11 (8%) test result records; eight (6%) registration or face sheet cards; 22 (16%) reports of disease occurrence; 12 (9%) records of status or condition (immunization and birth, marriage, or death certificates); 32 (23%) summary, evaluation, or survey

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analyzed forms of the Division of Communicable and Venereal Diseases and the Division of Health and Vital Statistics. About 10 forms are involved.

reports of services, programs, or institutions; three (2%) summary, evaluation, or survey reports of availability of services, programs, or institutions; and one record of disposition.

Of 31 forms applying to geographic regions, seven refer to the state as a whole, 12 to regions within, and one to cities or towns. One offers close-ended geographic codes and 11 give no information on the geographic area covered.

Of 30 forms recording measures of service, 20 refer to the number of patients served, seven to the number of tests done, two to the number of people screened. One measures service in another way.

Of 32 forms recording measures of outcome, four refer to the number of cases discharged, four to the number of people referred, eight to the number of tests showing positive, and two to the number of deaths. Fourteen do not specify the measure of outcome expected.

Of 75 record forms referring to individuals, six give sufficient information to permit linkage of individual records between divisions of the Department. They provide either name, exact birth date, and place of birth or the social security number. The six forms are distributed as follows among the divisions of the Department: one out of 12 forms is used in Adult Health; two out of five forms are used in Health and Vital Statistics; one out of 56 forms is used in Maternal and Child Health Services; one

out of 19 forms is used in Sanatoria and Tuberculosis Control; and one form is from Lemuel Shattuck Hospital.

Of 75 record forms referring to individuals, 15 give sufficient address information to permit linkage of individual records to the exact address and thereby allow flexible aggregation of individual records within geographic areas smaller than the city or town. The 15 forms are distributed as follows among the divisions of the Department: three out of 12 forms in Adult Health; three out of 21 forms in Communicable and Venereal Diseases; five out of five forms in Health and Vital Statistics; and four out of 19 forms in Sanatoria and Tuberculosis Control.

Cross-tabulations of data coded from the 139 forms studied by "Fact Finding for Comprehensive Health Planning in Massachusetts" indicate as much variation in definitions as the present study revealed among the 114 forms it analyzed.

Changes Needed to Achieve Compatibility

As previously mentioned, incompatible definitions or coding schemes interfere with the development of valid and reliable measures of qualities of people, organizations, and geographic areas. They may impede comparison of different sets of data and prevent aggregation and merging of files of data gathered from a variety of sources.

Analysis of forms in isolation reveals two major questions relating to the compatibility issue. First, when should an item

be included in a form? Second, what definition or coding scheme should be adopted for the item? Answers to these questions require knowledge about the goals which specific forms are meant to achieve, singly and in combination with others.

Variations in the items which are included in forms of the same title or subject matter can mean a number of things: (1) slightly different goals to be achieved, (2) differences of opinion about the information required to achieve the same goal, or (3) oversight or ignorance about the information required to achieve a specific goal. It would be arrogant for an "outsider" to venture an uninvited opinion about such matters.[15] Instead, the present discussion focuses on compatibility of definition among forms requesting the same item of information--and the means of achieving it.

It is clear that any organization wishing to compare information on the population it serves with a standard must turn to general population statistics compiled by the Bureau of the Census. In this way, judgments can be reached about the degree

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[15]The nine information systems studied in depth are undergoing revision and change. Substantive experts and/or consulting firms have been active participants in the process. In most instances, both substantive knowledge and systems analysis techniques are required to achieve articulation and coordination of data in order to serve the interests and needs of personnel in all parts of the organizations. Weinerman and his associates at Yale-New Haven Hospital and the Yale Department of Epidemiology and Public Health exemplify the approach and efforts required to achieve a thoroughgoing information system. (See E. Richard Weinerman, et al., "A System of Records and Statistics for Out-

of "fit" on some variable between the general population and the population served. Such information about the degree of "fit" has significance from the standpoints both of epidemiology and planning. High and low risk populations are discovered; whether programs are reaching the populations for which they are intended is also revealed.

The discussion which follows assumes that achieving comparability with general population statistics is a goal of sufficient importance to administrators, planners, and researchers to induce them to adopt definitions and coding schemes necessary to attain that goal as a minimum objective. To the extent that health and welfare organizations do adopt common definitions for a few key variables, compatibility, comparability, and flexible geographic-based record matching and linkage will have been achieved on

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patient Clinics As a Basis for Administration and Research" [Arlington, Virginia: Public Health Service, Division of Medical Care Administration, U.S. Department of Health, Education, and Welfare, February 1968].)

Analyses of changes in the nature of ambulatory medical care, problems in current systems of administrative and medical recording, and potential applications for operational and special research all contributed to the conceptualization and development of "a systematic and efficient method of collecting, storing and analyzing information on the operation of ambulatory services in hospitals or independent clinics." (Ibid., p. 2.) The system devised collects five categories of data in form permitting comparison of (1) demographic and socioeconomic characteristics of patients, (2) diagnostic and therapeutic information about patients, (3) utilization of services and facilities, (4) costs of services, clinic income, and expenses, and (5) attitudes of patients concerning their care and treatment, with community-wide and national statistics.

those variables. This would set the scene for meaningful exchange of statistics and aggregated sets of data without raising the issue of individual confidentiality or privacy. The tension between corporate privacy and corporate accountability and disclosure, however, will still remain.

In line with these considerations, it is recommended that health organizations and related agencies in Metropolitan Boston and other areas be urged to incorporate 10 items of information as defined by the Bureau of the Census into the following types of records: (1) composite records from which abstracts may be taken, (2) forms for abstracting data from composite records, and (3) forms which are to be used directly for gathering data for comparative purposes. The items are: (1) relationship to head of household, (2) color or race, (3) age (month and year of birth), (4) sex, (5) marital status, (6) state or country of birth, (7) years of school completed, (8) employment status, (9) occupation, and (10) either year moved into present dwelling unit or place of residence five years ago.[16]

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[16] See Bureau of the Census, Data Access Description, Collection, Evaluation and Processing Series, CEP-1 [Washington, D.C.: U.S. Department of Commerce, July 1968], pp. 2-11 for items and their exact definitions. The first 5 items of information are obtained on 100% of the population; the remainder are gathered on a 25% sample. These measures are recognized as important actuarial and social indicators. Life tables, epidemiological estimates, indices of socioeconomic status, and geographic mobility are constructed from them. Though certainly relevant, income is not recommended for inclusion for two probably related reasons: (1) it is practically impossible to obtain income figures reliably and

It is further recommended that exact address by number, street, and city or town be obtained in preparation for flexible geographic-based record linkage by means of the DIME file or other computerized address coding scheme.

These recommendations should be adopted by the first health, welfare, and police subsystems that emerge in Metropolitan Boston and the state. Leadership taken by Blue Cross-Blue Shield, United Community Services, the Executive Office of Administration and Finance, and the office of the attorney general is likely to shape the future for some time to come.

Meanwhile, if one may extrapolate the findings of the forms analysis presented above to other health and welfare organizations, it is apparent that a good job of housecleaning must necessarily precede design and development of anything resembling Hearle's dream of an "urban management information system." Hearle himself had this fact in mind; he concludes his paper on "Urban Management Information Systems" with a plea for developing improved data bases rather than exotic computer analysis techniques:

> We do not yet have in organized, manageable, current, comprehensive fashion sufficient urban data to feed the models which are being conceived and advocated. Let us move ahead on both fronts, but let us put first the development of relevant data bases for operations and analysis, and put second the refinement of analytical techniques. Fortunately, we can rely on our academic colleagues for attention to the second area, so the majority of public agency resources can be allocated to the first.[17]

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without resentment outside of a bank, finance company, or office of the Internal Revenue Service and (2) none of the forms analyzed asked for income in any guise.

[17]"Urban Management Information Systems," p. 15.

CHAPTER V

INVENTORY OF RECORD-KEEPING AND PROCESSING RESOURCES IN SELECTED HEALTH AND RELATED ORGANIZATIONS

Introduction

The current revolution in data processing has raised numerous questions concerning the impact of automation upon health organizations and related agencies in Metropolitan Boston.

To learn what the present situation is in this field and to help determine the ability and willingness of these groups to participate in a computer-based health and welfare information network, the initial phase of the inquiry undertook an inventory of record keeping and processing within relevant organizations.

This phase, conducted from September 1967 through February 1968, sought to obtain an overview of the different types of health and related organizations in the area and to find answers to certain specific questions. These included:

1. How do the health organizations and related agencies which have been selected compare in terms of size (measured by number of employees), patients or clients served, and annual budgets?

2. What organizational structures have been evolved for processing data?
3. How much manpower is involved in record keeping and processing?
4. What are the costs?
5. What types of equipment and materials are used?
6. To what extent have record keeping and processing been automated?
7. What are organizational policies and practices regarding release and sharing of information?
8. How ready are these groups to make the transition to information sharing via the computer?
9. Are machine-readable data available for immediate storage and use in the event a potential network includes an archive (a data bank)?
10. What are the similarities and differences among organizations of different types and sizes on the above-mentioned points?

The information gained from the inventory was expected to yield needed knowledge on existing record-keeping and processing systems, however crude or sophisticated they might be. It was expected, also, that it would permit more critical judgment about which organizations were suited for linkage into subsystems prior to ultimate coupling to a community-wide health and welfare information system.

In addition, information gained from the inventory was needed for guidance in choosing a manageable number of organizations which were to be under closer study during the later in-depth phase. Limited resources made it necessary to restrict the number selected to eight or 10. Relative size and importance, from the standpoint both of serving large segments of the population and of potentially influencing other organizations to join an information system--plus an organization's degree of expertise in record keeping and processing--appeared to be strategic criteria for making the selection. Ten organizations eventually were chosen for the later in-depth phase of study, which is reported in subsequent chapters.

Method

A Task Force on Scope was appointed by the Joint Center Health Information System Advisory Committee to describe the universe of relevant health and related organizations in Metropolitan Boston. A total of over 200 individual organizations and categories of organizations was listed.[1] Every organization specifically named was contacted. The choice of which organizations to contact within the various categories was made based upon advice from members of the task force and other authorities.

For example, the Task Force on Scope specified health departments in Brookline and Newton, plus the combined health department of Weston, Needham, and Wellesley. It referred to "approximately

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[1]See Appendix A for complete list.

70 other local health departments." Of the 70 others, seven were contacted after consultation because they were considered representative of health departments manned either by physicians with public health training or by physicians without such training. Commercial laboratories and pharmacies, although listed, were excluded from study because they did not seem as immediately relevant as other health and related organizations.

Neither the method of describing the universe of elements to be sampled nor the method of sampling the universe, once defined, permits statistically valid representation of the whole universe of relevant health and related organizations in Metropolitan Boston. The list was not exhaustive; and judgment sampling of elements within categories of organizations prevents the calculation of error that is possible when estimates have been derived from sample data. However, these deficiencies are not considered very important.

The purpose of the undertaking was to study selected health organizations and related agencies in the Boston region from the standpoint of their ability and willingness to participate in a health and welfare information system. Implicit in the very process of selecting organizations for study were judgments about the importance of their potential contributions to a network or system. The usefulness and success of any system to be developed would depend upon its participating organizations. A significant number of key health and related organizations, judgmentally listed and sampled, would have to interested, able, and willing to

participate; if not, the decisions of smaller and less influential organizations would be irrelevant.

A telephone interview guide was developed to insure that telephone inquiries systematically covered all pertinent items of information.[2] The number of organizations to be contacted made communication by telephone or letter necessary. The executive contacted was given the option of delegating responsibility for providing the information requested. Respondents sometimes requested and received a formal letter explaining the nature of the inquiry and its auspices, as well as a copy of the telephone interview guide.

Obtaining the desired information posed major difficulties. Telephone interviewers usually were shunted from the executive to person after person up and down the organizational hierarchy. This occurred because personnel and costs associated with record keeping and processing are not customarily separated from overall departmental and program budgets. When inconsistencies in information from several sources were noted, clarification became a necessary and time-consuming task.

The following brief description of the accounting procedure necessary to derive accurate cost estimates for record keeping and processing within a large hospital center is typical of the complexities involved. First, it was necessary to identify basic

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[2]See Appendix D for copy.

departments or units concerned with record keeping and processing within the organization. Then, for each department or unit, the number of people employed, the payroll, operating expenses, capital investment in equipment prorated for the year of estimate, and costs per year of space occupied were calculated. The sum of the above costs yields an estimate of total costs of record keeping and processing per hospital or organization. Table 11 presents the results of a cost analysis of record keeping and processing in a large hospital center.

TABLE 11

RECORD-KEEPING AND PROCESSING COSTS IN A LARGE HOSPITAL CENTER

			Items		
Department	No. People	Payroll	Operating Expenses	Capital Equip.	Space ($5 per sq. ft. per yr.)
General Accounting	9.2	$ 55,729	$ 7,650	$10,000	$ 30,000
Accounts Payable	6.0	32,168	1,150	4,000	15,000
Credit	15.5	85,562	39,900	15,000	40,000
Medical Records	40.3	187,034	13,400	25,000	50,000
Personnel	9.0	61,189	45,000	5,000	30,000
Systems-Computer	16.8	111,745	86,864	20,000	25,000
TOTAL	96.8	$533,427	$193,964	$79,000	$190,000

GRAND TOTAL $996,391

Theoretically, every organization followed a similar procedure in estimating costs. It would be naive, however, to assume that every organization provided as detailed an estimate as the large

hospital center cited. In all likelihood, estimates were based upon the salaries of persons involved in record keeping and processing and upon a percentage of the operating expenses of the department or unit in which they worked. Capital expenditures for equipment, unless highly visible, were subsumed, probably, under operating expenses, while the cost of space occupied by the department or unit escaped notice. It seems reasonable, therefore, to make the assumption that cost estimates for record keeping and processing were largely underestimated by the organizations studied. Short of a full and focussed audit, first approximations are necessarily crude. Uncertainty about the methods used by respondent organizations to derive cost and personnel estimates constitutes the major limitation of the inventory.

Information on the total number of persons served, total number of employees, and total budget was extracted from annual reports wherever possible. Since these data are matters of public record, their collection from annual reports appeared to be the most sensible and efficient approach. However, annual reports were not always up to date, nor was the request for a copy always honored. In several instances, equivalent materials substituted for an unobtainable or out-of-date report. In a few cases, reports were refused or were promised but not sent. Gaps in the data are also due to the inability of some organizations to provide estimates in the form requested. For example, hospitals uniformly were unable to reduce outpatient visits to the number of persons served since many patients make multiple visits. Also, local health depart-

ments could offer only partial estimates of persons served; the remainder were in terms of the number of tests or procedures administered. Thus, complete sets of data on every organization were not always available for analysis.

All the organizations contacted provided at least part of the information sought, thereby making partial data available for statistical analysis. Missing data were coded as blanks and omitted from calculation of measures of central tendency, variance, and association. Categories of information not applicable to all the organizations were treated similarly. In the presentation of findings below, reference is made to those circumstances which account for inconsistent numbers underlying statistical measures. When they occur, missing data are a source of error in the estimates.

For purposes of comparison, groups of organizations--roughly homogeneous--were formed from the task force's list of organizational categories. Whenever possible, the groups were subdivided by size as measured by the number of personnel employed. Size clusterings, empirically derived, guided subdivision into larger and smaller organizations of a type. In one or two instances, disparity in size was so great that only one organization out of several fell into the larger group. In two other instances, the number and relative size of the organizations were so small that no subdivision was possible.

Definitions

Organizations were initially classified by type according to the specifications of the Joint Center Health Information

System Advisory Committee through its Task Force on Scope. The universe of health and related organizations was divided into four major categories and then subdivided again by legal status: (1) health planning agencies--public (official) and voluntary; (2) general planning agencies with health-related interests--public and voluntary; (3) health service agencies--public, voluntary, proprietary or commercial, and university-related; and (4) non-health service agencies with a health component--public and voluntary.

However, for analytical purposes it was necessary to classify the organizations in a different manner.[3] Twelve types of organizations resulted from reclassification, 10 of which were subdivided by size. The 12 types are as follows: (1) hospitals, (2) planning agencies (e.g., Massachusetts Hospital Association and United Community Services), (3) university-related agencies (e.g., the Joint Center for Urban Studies of MIT and Harvard University and the Harvard School of Public Health), (4) public social agencies (e.g., Massachusetts Youth Service Board and the State Department of Correction), (5) local welfare departments, (6) visiting nurse associations, (7) private social agencies (e.g., Family Service Association of Greater Boston and Catholic Charitable Bureau), (8) nursing homes, (9) mental health clinics, (10) local health

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[3]Classification by major category and legal status in every instance resulted in a sample numerically too fragmented and heterogeneous for stable measurement and statistical comparisons.

departments, (11) registry and regulatory boards (e.g., the State Department of Civil Service and Registration and the State Rate-Setting Board for Nursing and Convalescent Homes, and (12) state research and statistical units (e.g., the Division of Health and Vital Statistics and the Statistical Unit, Division of Adult Health of the Massachusetts Department of Public Health).

Record-keeping and processing operations fell into four basic categories: (1) patient or client records, (2) accounting, (3) research, and (4) automatic data processing (ADP). Organizations with sufficient paper work to justify specialization had developed more formal departmental structures. Less burdened organizations were able to manage without as much specialization and structure.

In this report, the four above-mentioned categories have been defined as follows: Patient or client records refer to medical and case records containing information of a clinical or personal nature about individuals. Accounting refers to accounts payable and receivable, and to payroll. It has been used, as well, to denote the disbursement function in agencies offering financial support. Research refers to the collecting and processing of data for the purpose of expanding knowledge (in contrast to furtherance of service goals). Automatic Data Processing (ADP) refers to use of off-line equipment such as card punches, sorters, collators, reproducers, and interpreters for data processing. It does not include the use of electronic computers, although such use often

requires preparatory work on ADP equipment. It is possible for an organization to use ADP equipment without recourse to a computer.

Several conventions, or definitions, were adopted for recording information on record-keeping and processing operations. An operation was considered a structurally distinct department when reported as such or contained in a separate section, room, or business office. The number of full- and part-time personnel and expenditures relates to departments whenever applicable; otherwise, this information relates to the relevant operation or activity within the organization.

Total number of full- and part-time personnel and total expenditures in all categories of record keeping and processing, when combined, include employees and expenditures in individual records, accounting, and ADP, in addition to other related employees and expenditures not covered by those categories--most notably, research. It was necessary to take this approach with respect to research because non-departmental research proved extremely difficult to isolate in terms of personnel and expenditures. Again, a few smaller agencies could not separate individual records from the accounting operation. Therefore, the personnel and expenditures relating to these unseparated operations are represented as part of the total of all categories of record keeping and processing combined. Whenever ADP was not considered a separate department but part of another, the number of employees

and expenditures for ADP have been isolated from the rest of the department, and figures for the remainder have been adjusted commensurately.

It was not possible to obtain comparable estimates of the number of persons served during the last fiscal year from every organization. For example, as noted previously, hospital outpatient statistics in terms of visits could not be reduced to the number of patients served. Therefore, the outpatient count was eliminated and the number of inpatient admissions during the last fiscal year was accepted as the measure of the number of persons served. This, of course, under-represents the activity level of hospitals when compared to other organizations for which full estimates of service were available. The distortion is likely to be less when making comparisons among hospitals. However, hospitals in which the scale of outpatient activities does not parallel inpatient activities will suffer some degree of over- or under-representation in these comparisons. The fact that hospital and nursing home admissions are duplicated counts of the number of persons served is another source of error, the magnitude of which is unknown.

Some organizations could only offer "family cases" as the closest approximation of the number of persons served. In order to estimate the number of persons involved, such cases were multiplied by 3.56, the average number of persons per family in the northeast region of the United States, according to U.S. Census Bureau statistics. This is probably an understated figure since

there is some evidence that larger families are over-represented in these agencies. A similar procedure was used in reducing the "family cases" in General Relief and in Aid to Families with Dependent Children to individuals. The average family size for various welfare categories, as cited by public welfare departments, was used as a multiplier.

Finally, a few organizations, most notably local public health departments, presented statistics on annual activities in such a way that reconstruction of the number of persons served was impossible. The number of visits, persons, and tests or other procedures was intermingled in annual reports of these agencies. No attempt was made to estimate the number of persons they served.

The total number of personnel employed by the various organizations refers to full-time employees or the combination of full-time and part-time employees. Part-time employees were expressed as full-time equivalents according to the ratio: two part-time employees equal one full-time employee.

Most recent budget total refers to total operating expenses for the last fiscal year. For most organizations, the time period involved was either July 1, 1966, to June 30, 1967, or the calendar year, January 1, 1966, to December 31, 1966. As a rule, however, hospitals reported operating expenses for the period October 1, 1966, to September 30, 1967. In cases where organizations offered financial support or paid claims on insurance policies, such sums were excluded from the total budget. Total budget

was confined to the costs of administering programs of various types for the year.

When ADP equipment and materials and/or the computer were used, application or use of such equipment took three basic forms: (1) equipment was located and used in-house; (2) equipment was located elsewhere but staff initiated application; that is, staff either contracted with others to program jobs on a computer or programmed the jobs themselves; and (3) equipment was located elsewhere, and national or supervisory organizations initiated application; that is, these larger organizations required from their affiliates or local units data in a form compatible with easy machine processing. It should be noted that when staff initiated use of electronic data processing equipment, it involved either direct interaction of staff with personnel and equipment in local computation facilities or the purchase of payroll accounting services.

ADP and/or computer use, irrespective of location or who initiated application, may be either for general purposes or strictly for accounting. In-house use of equipment implies direct administrative responsibility for equipment, technical personnel, supplies, and upkeep. It entails capital outlay for equipment by purchase or lease.

Selected Organizations Providing Health and Related Services in Metropolitan Boston

The first question to which the inquiry sought an answer

was: How do the health organizations and related agencies which have been selected compare in terms of size (measured by number of employees), patients or clients served, and annual budgets? These findings follow:

Organizational Size

Hospitals, planning agencies, university-related agencies, public social agencies, private social agencies, local welfare departments, visiting nurse associations, nursing homes, mental health clinics, local health departments, registry and regulatory boards, and state research and statistical units were queried.[4] Of these, 175 organizations have been analyzed. They were divided into roughly similar groups, then subdivided by size as measured by the number of persons employed. Hospitals comprise the largest proportion of organizations, numbering 52.

In terms of size, the majority of hospitals, 37 in all, employed between 100 and 1,000 persons each. Nine employed more than 1,000 and six, less than 100. Seven planning agencies employed more than 400 persons; 13 employed less than 400. For the most part, mixed planning and service functions distinguished the seven larger planning agencies from the rest. Blue Cross and the State Department of Public Welfare, for example, were designated

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[4] One hundred eighty-four organizations were queried. Nine were eliminated from the present analysis either because the data on them were too fragmentary and unreliable or because they were considered too small a subdivision of a larger organization to analyze as a separate unit. See Appendix A for complete list.

as planning agencies. Among university-related agencies, the greater number employed less than 300 persons; four of the 14 university-related agencies employed more than 300.

Six of the eight public social agencies employed under 200, while nine of the 15 private social agencies had under 50 employees. Six private social agencies employed more than 50 persons. Most mental health clinics employed fewer than 50 persons; only eight of the 23 mental health clinics queried employed more than 50.

Six nursing homes were surveyed; four employed more than 50 persons. Nine local health departments employed more than 25 persons; four employed less. One of the eleven visiting nurse associations had more than 100 employees; the remainder, less than 100. There were too few registry and regulatory boards and state research and statistical units to subdivide by size. Registry and regulatory boards employed an average of 139 persons each, while state research and statistical units averaged 16 each.

Table 12 presents in detail the total number of employees, patients and clients served annually, and employee-to-patient or employee-to-client ratios for each type of organization by size. The standard deviations associated with the mean values reported in Table 12 indicate considerable variability of measurement within the various groups of organizations. This occurred, in part, because a small number of cases was involved in the calculations. Accordingly, the mean values reported should be regarded as very

TABLE 12

TOTAL NUMBER OF EMPLOYEES, PATIENTS AND CLIENTS SERVED ANNUALLY, AND EMPLOYEE-PATIENT/CLIENT RATIOS

Type Organization by Size (No. Employees)	N[a]	Number Employees			Number Patients/Clients			Employee-Patient/Client Ratios		
		N[b]	Mean	SD[c]	N[b]	Mean	SD[c]	N[b]	Mean	SD[c]
Hospitals (≥ 1,000)	9	9	1,779.9	1,059.7	9	13,652.6	8,485.5	9	.15	.07
Hospitals (500-999)	15	15	742.1	157.0	15	7,348.5	4,288.7	15	.27	.43
Hospitals (100-499)	24	22	303.9	129.7	22	2,734.5	2,844.3	22	.28	.26
Hospitals (< 100)	6	6	53.5	32.9	4	870.3	461.1	4	.07	.02
Planning agencies (≥400)	7	7	1,115.9	833.9	4	359,045.0	453,474.4	4	.01	.02
Planning agencies (<400)	15	13	42.1	26.8	1	15,191.0	0.0	1	.01	.00
University-related agencies (≥300)	4	4	745.5	346.0	0	----	----	0	---	---
University-related agencies (< 300)	10	10	43.0	41.5	0	----	----	0	---	---
Public social agencies (≥ 200)	2	2	1,513.5	1,079.7	1	3,000.0	0.0	1	.25	.00
Public social agencies (<200)	6	6	102.3	37.7	4	63,137.5	41,276.0	4	.01	.02
Local welfare depts. (≥100)	2	2	556.0	627.9	2	47,916.5	59,515.1	2	.02	.01
Local welfare depts. (<100)	4	4	21.7	15.7	4	2,261.5	2,673.5	4	.01	.01

TABLE 12--Continued

Type Organization by Size (No. Employees)	N[a]	Number Employees			Number Patients/Clients			Employee-Patient/Client Ratios		
		N[b]	Mean	SD[c]	N[b]	Mean	SD[c]	N[b]	Mean	SD[c]
Visiting nurse assns. (≥100)	1	1	146.0	0.0	1	10,511.0	0.0	1	.01	.00
Visiting nurse assns. (<100)	10	10	7.0	3.8	7	767.0	553.6	7	.01	.01
Private social agencies (≥50)	6	6	76.3	39.9	4	17,512.8	17,364.7	4	.02	.02
Private social agencies (<50)	9	9	29.9	17.5	7	7,262.8	7,968.6	7	.01	.01
Nursing homes (≥50)	4	4	67.5	9.0	2	191.0	104.8	4	.47	.32
Nursing homes (<50)	2	2	41.0	8.5	2	125.0	21.2	2	.33	.01
Mental health clinics (≥50)	8	8	51.1	31.1	8	644.3	97.0	5	.08	.06
Mental health clinics (<50)	16	15	10.5	3.9	15	573.5	403.8	15	.03	.02
Local health depts. (≥25)	4	4	46.3	18.4	0	----	----	0	---	---
Local health depts. (<25)	10	9	7.0	3.6	0	----	----	0	---	---
Registry/regulatory boards	7	3	139.0	138.3	2	182,500.0	130,814.7	2	.00	.00
State research/statistical units	4	4	15.7	5.1	0	----	----	0	---	---

[a]N refers to total number of organizations for which information was applicable.

[b]N refers to the total number of organizations for which information was available for computing the values reported.

[c]SD refers to standard deviations.

crude summaries of the underlying data.[5]

Patients or Clients Served

Annual service statistics showed considerable difference in activity levels among the various types of organizations. Among hospitals, the average number of patients served increased as the average number of employees increased. Four of seven larger planning agencies performed dual functions of planning and serving clients, while only one of 13 smaller planning agencies did so. Excluding education, none of the university-related agencies and state research and statistical units had a direct-service function. Data were missing for some of the public social agencies. However, available data indicate that the smaller public social agencies served, on the average, the larger number of clients. For the remainder, ignoring missing data, there was a direct positive relationship between the number of employees and the number of patients or clients served. Without exception, service data were missing for local health departments.

The average employee-to-patient or employee-to-client ratio was calculated for each group of organizations. Although these

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[5]Alternate methods of displaying the data might have been employed. Actual distributions of values for each organization could have been shown, or separate tables of values by organizational type and by organizational size could have been presented. The expedient of giving values for types of organizations graded by size was used because it showed simultaneously--although impressionistically--the relationship between organizational type and size and other study variables.

data were missing and/or inappropriate for five groups of organizations, some generalizations appear warranted. Nursing homes had the largest average employee-to-patient ratio, ranging from .327 to .470 employees per patient. As a group, hospitals ranked second on average employee-to-patient ratios, although the smallest hospitals had a relatively small ratio; that is, they had many more patients than employees. Among hospitals, medium-size institutions had the largest ratios--roughly .3 employees per patient. It should be remembered, however, that inability to represent outpatients in these calculations has inflated the figures, which may actually fall within the range of values representing the rest of the organizations queried. The remainder of the direct-service organizations, except public social agencies with more than 200 employees, had very small employee-to-patient or employee-to-client ratios. These ratios were .082 and less.

Total Annual Budgets

Total annual budgets provided an index of differences in financial resources and activity levels among the organizations studied. The nine largest hospitals had average annual expenditures of $14,093,420 per year. Ranking a close second, third, and fourth, respectively, were seven larger planning agencies ($13,764,090), two larger public social agencies ($11,530,050), and four large university-related agencies ($10,975,030). A large gap in total annual budget existed between these organizations and the next cluster. Two groups of medium-size hospitals

spent an average of $5,476,410 and $2,294,140. Two larger welfare departments averaged $2,847,600, and three registry and regulatory boards, $1,030,330.

As shown by Table 13, the rest of the organizations spent less than $1 million per year, on the average; the smallest organizations, much less. The smaller mental health clinics, local health departments, and visiting nurse associations had average annual budgets of less than $100,000 per year. The aforementioned differences and the standard deviations associated with the total annual budgets presented indicate, in capsule, wide variations in resources between and within the various types of organizations.

Organizational Structure for Record Keeping and Processing

The inquiry next wanted to learn: What organizational structures have been evolved for processing data?

It was found that, as a group, hospitals exceeded other organizations in structuring record keeping and processing into distinct departments. As shown by Table 14, all of the largest hospitals had a department for patient records as did over 75 percent of the medium-size hospitals. However, none of the smallest hospitals had such a department.

A small percentage of other types of organizations had departments for patient or client records, and these were usually the larger organizations. University-related agencies, visiting

TABLE 13

TOTAL ANNUAL BUDGETS BY TYPE OF ORGANIZATION AND SIZE

Type Organization by Size (No. Employees)	N[a]	Total Annual Budgets ($100 Units) N[b]	Mean	SD[c]
Hospitals (≥1,000)	9	9	140,934.2	182,533.8
Hospitals (500-999)	15	15	54,764.1	16,871.5
Hospitals (100-499)	24	20	22,941.4	9,479.9
Hospitals (< 100)	6	5	3,496.2	2,672.3
Planning agencies (≥400)	7	7	137,640.9	118,898.4
Planning agencies (< 400)	15	13	9,508.8	17,251.4
University-related agencies (≥ 300)	4	4	109,750.3	88,206.3
University-related agencies (< 300)	10	8	3,043.6	2,542.0
Public social agencies (≥200)	2	2	115,300.5	85,277.8
Public social agencies (< 200)	6	6	7,147.2	2,156.0
Local welfare depts. (≥100)	2	2	28,476.0	30,439.5
Local welfare depts. (< 100)	4	4	1,654.7	1,637.0
Visiting nurse assns. (≥100)	1	1	8,976.0	0.0
Visiting nurse assns. (< 100)	10	10	417.5	333.8
Private social agencies (≥50)	6	6	7,303.5	3,436.4
Private social agencies (< 50)	9	9	2,815.1	1,843.5
Nursing homes (≥50)	4	4	3,073.5	1,087.1
Nursing homes (< 50)	2	2	2,130.5	1,219.8
Mental health clinics (≥25)	8	8	3,000.4	1,848.4
Mental health clinics (< 25)	16	13	871.8	374.6
Local health depts. (≥25)	4	4	3,262.5	662.3
Local health depts. (< 25)	10	9	706.3	539.5
Registry/regulatory boards	7	3	13,972.7	14,572.9
State research/statistical units	4	4	1,322.7	506.6

[a]N refers to total number of organizations for which information was applicable.

[b]N refers to the total number of organizations for which information was available for computing the values reported.

[c]SD refers to standard deviations.

TABLE 14

ORGANIZATIONAL STRUCTURE FOR RECORD KEEPING AND PROCESSING

Type Organization by Size (No. Employees)	N[a]	N[b]	Records Dept. % Having	Accounting Dept. % Having	ADP Dept. % Having	Research Dept. % Having
Hospitals ($\geq$ 1,000)	9	9	100	100	44	0
Hospitals (500-999)	15	15	93	100	20	13
Hospitals (100-499)	24	22	77	73	4	14
Hospitals ($<$ 100)	6	6	0	17	0	0
Planning agencies ($\geq$400)	7	7	14	71	29	43
Planning agencies ($<$ 400)	15	13	15	15	8	31
University-related agencies ($\geq$300)	4	4	0	0	0	0
University-related agencies ($<$ 300)	10	10	0	0	0	0
Public social agencies ($\geq$200)	2	2	50	50	50	50
Public social agencies ($<$ 200)	6	6	33	17	0	33
Local welfare depts. ($\geq$100)	2	2	50	50	0	50
Local welfare depts. ($<$ 100)	4	4	0	25	0	0

TABLE 14--Continued

Type Organization by Size (No. Employees)	N[a]	N[b]	Records Dept. % Having	Accounting Dept. % Having	ADP Dept. % Having	Research Dept. % Having
Visiting nurse assns. ($\geq$100)	1	1	0	0	0	0
Visiting nurse assns. ($<$100)	10	10	0	0	0	0
Private social agencies ($\geq$50)	4	6	33	17	17	33
Private social agencies ($<$50)	9	9	11	0	0	11
Nursing homes ($\geq$50)	4	4	0	0	0	0
Nursing homes ($<$50)	2	2	0	0	0	0
Mental health clinics ($\geq$25)	8	8	0	0	0	25
Mental health clinics ($<$25)	16	15	0	0	0	0
Local health depts. ($\geq$25)	4	4	0	0	0	0
Local health depts. ($<$25)	10	9	0	0	0	0
Registry/regulatory boards	7	3	33	0	67	0
State research/statistical units	4	4	0	0	0	0

[a]N refers to total number of organizations for which information was applicable.

[b]N refers to the total number of organizations for which information was available for computing the values reported.

nurse associations, nursing homes, mental health clinics, local health departments, the smaller local welfare departments, and the state research and statistical units did not have departments for patient or client records. Size and function appear related to the existence of such departments. Larger, direct-service organizations tend to have them; smaller organizations, no matter what their function is, do not.

With respect to accounting, the situation closely paralleled that of patient or client records. The largest hospitals, again, had separate accounting departments as did one of the smallest hospitals. Larger organizations with responsibility for large payrolls and/or billing operations tended to have separate accounting departments.

Relatively few organizations had a separate department for automatic data processing. Separate ADP departments were concentrated in the larger hospitals. However, they were also found in two of the three registry and regulatory boards, in two of the larger planning agencies, and in one each of the smaller planning agencies, larger public social agencies, and larger private social agencies.

Few organizations maintained a separate research department. Those which existed were found primarily in planning agencies and in public and private social agencies. University-related agencies organized their research by project rather than by department.

Record-Keeping and Processing Personnel

A third area which needed clarification and to which the inquiry directed itself was: How much manpower is involved in record keeping and processing?

Data on the number of full- and part-time personnel in various types of record-keeping and processing operations were difficult to obtain, and they present a fragmentary picture of the distribution of manpower in data processing. As shown by Table 15, most organizations employed full-time rather than part-time staff to keep and to process records.[6] Organizational size was directly related to the number of personnel employed in every type of record-keeping and processing operation. On the average, more personnel were employed in accounting operations than in patient or client records and ADP. Records ranked second in the number of persons employed.

Relatively few organizations employed personnel for automatic data processing. Of those which did, the most notable were the hospitals. Six of the nine largest hospitals employed an average of 16 persons each for ADP; eight of 14 hospitals ranking second in overall size employed an average of 7.7 persons; and four of 22 smaller hospitals averaged 3.7 persons in ADP. Four larger planning agencies employed an average of 31.5 persons. The two registry and regulatory boards with ADP departments averaged 7.5 employees. One

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[6]Consolidation of estimates in terms of full-time equivalence of part-time personnel may account, in part, for this finding.

TABLE 15

FULL- AND PART-TIME PERSONNEL IN RECORD KEEPING AND PROCESSING BY TYPE OF OPERATION

Type Organization by Size (No. Employees)	N[a]	Patient/Client Records: No. Full-Time N[b]	Mean	Patient/Client Records: No. Part-Time N[b]	Mean	Accounting: No. Full-Time N[b]	Mean	Accounting: No. Part-Time N[b]	Mean	Automatic Data Processing: No. Full-Time N[b]	Mean	Automatic Data Processing: No. Part-Time N[b]	Mean
Hospitals (≥1,000)	9	9	33.9	3	17.0	9	34.1	3	8.3	6	16.0	1	2.0
Hospitals (500-999)	15	14	12.9	6	6.5	15	18.5	3	2.0	8	7.7	0	----
Hospitals (100-499)	24	22	5.0	6	1.7	22	9.0	6	4.0	4	3.7	1	3.0
Hospitals (< 100)	6	2	1.5	2	1.5	2	3.5	4	1.3	0	----	0	----
Planning agencies (≥400)	7	2	21.5	1	40.0	6	29.5	0	----	4	31.5	1	12.0
Planning agencies (< 400)	15	4	6.3	2	4.0	7	4.1	2	1.0	1	19.0	0	----
University-related agencies (≥300)	4	0	----	0	----	0	----	0	----	0	----	0	----
University-related agencies (< 300)	10	0	----	0	----	0	----	2	3.0	0	----	0	----
Public social agencies (≥200)	2	1	23.0	0	----	2	14.5	0	----	1	84.0	0	----
Public social agencies (< 200)	6	5	16.0	0	----	5	4.4	1	1.0	0	----	0	----
Local welfare depts. (≥100)	2	2	15.5	0	----	2	71.0	0	----	1	12.0	0	----
Local welfare depts. (< 100)	4	3	2.7	0	----	4	6.5	1	1.0	0	----	0	----

TABLE 15--Continued

Type Organization by Size (No. Employees)	N[a]	Patient/Client Records: No. Full-Time N[b]	Mean	Patient/Client Records: No. Part-Time N[b]	Mean	Accounting: No. Full-Time N[b]	Mean	Accounting: No. Part-Time N[b]	Mean	Automatic Data Processing: No. Full-Time N[b]	Mean	Automatic Data Processing: No. Part-Time N[b]	Mean
Visiting nurse assns. (≥100)	1	1	3.0	0	----	1	6.0	0	----	0	----	0	----
Visiting nurse assns. (<100)	10	0	----	0	----	0	----	0	----	0	----	0	----
Private social agencies (≥50)	6	3	3.7	3	6.0	6	3.7	1	1.0	1	5.0	0	----
Private social agencies (<50)	9	5	4.0	6	3.2	4	2.7	4	1.5	0	----	0	----
Nursing homes (≥50)	4	1	1.0	4	2.5	2	1.5	2	1.0	0	----	0	----
Nursing homes (<50)	2	0	----	2	5.0	0	----	2	2.0	0	----	0	----
Mental health clinics (≥25)	8	2	2.0	5	3.4	5	2.0	6	1.0	0	----	1	2.0
Mental health clinics (<25)	16	1	1.0	7	1.6	1	1.0	7	1.0	0	----	0	----
Local health depts. (≥25)	4	1	1.0	1	5.0	2	2.5	0	----	0	----	0	----
Local health depts. (<25)	10	0	----	4	1.0	1	1.0	3	1.0	0	----	0	----
Registry/regulatory boards	7	1	12.0	0	----	3	1.3	1	2.0	2	7.5	0	----
State research/statistical units	4	0	----	0	----	0	----	0	----	0	----	0	----

[a]N refers to total number of organizations for which information was applicable.

[b]N refers to the total number of organizations for which information was available for computing the values reported. Space does not permit reporting of standard deviations.

of the larger public social agencies reported 84 full-time persons in ADP. The only organizations which employed part-time personnel for ADP were one planning agency, two hospitals, and one mental health clinic.

University-related agencies, smaller visiting nurse associations, and state research and statistical units did not employ personnel for keeping records of patients or clients, although for different reasons. Public social agencies, local welfare departments, larger visiting nurse associations, and registry and regulatory boards reported only full-time personnel. Smaller nursing homes and smaller local health departments had part-time personnel only.

Larger university-related agencies, smaller visiting nurse associations, and state research and statistical units did not have staff committed to accounting operations. The larger planning agencies, public social agencies, local welfare departments, visiting nurse associations, and local health departments reported only full-time personnel. Smaller university-related agencies and smaller nursing homes employed only part-time personnel in accounting. Appropriateness of function and/or position of the organization within a larger organization, such as a university or the state government, partially influenced whether accounting personnel were employed.

Record-Keeping and Processing Costs

Still another question asked was: What are the costs of record keeping and processing?

As with the information gathered on manpower, the data on these costs are fragmentary. Many organizations were unable to provide estimates because such costs were subsumed under other budgetary items. It was difficult, therefore, to break out these costs for separate presentation. For the most part, organizations which reported the number of full- and part-time personnel in record-keeping and processing estimated costs. One larger public social agency, which spent $208,200 processing client records, stands out from the rest. Some hospitals spent almost as much on patient records. In fact, hospitals in general spent more on records concerning individuals than any other type of organization. Table 16 indicates expenditure levels of the various organizations by type of record-keeping and processing operation. Nursing homes spent the smallest amount on patient records and accounting. Not unexpectedly, smaller organizations tend to spend less than larger organizations.

The costs accrued by organizations for accounting generally paralleled the pattern of organizational expenditures for patient or client records. Larger local welfare department expenditures for accounting appeared to approximate hospital levels. Although many organizations did not incur costs for ADP, those which did spent more on ADP than on patient or client records and on

TABLE 16

COSTS OF RECORD KEEPING AND PROCESSING BY TYPE OF OPERATION

Type Organization by Size (No. Employees)	N[a]	Patient/Client Records Cost ($100 Units)			Accounting Cost ($100 Units)			ADP Cost ($100 Units)		
		N[b]	Mean	SD[c]	N[b]	Mean	SD[c]	N[b]	Mean	SD[c]
Hospitals (≥1,000)	9	9	1,731.2	1,216.8	9	2,106.4	1,609.8	6	1,608.2	836.1
Hospitals (500-999)	15	15	672.3	262.8	15	1,214.9	593.1	8	507.4	352.1
Hospitals (100-499)	24	21	289.3	179.6	20	580.1	343.7	5	212.6	239.3
Hospitals (<100)	6	2	89.0	48.1	2	210.0	38.2	0	-----	-----
Planning agencies (≥400)	7	3	940.0	694.0	6	1,692.7	1,303.9	5	2,467.6	4,230.0
Planning agencies (<400)	15	5	300.0	209.2	8	213.7	245.1	3	2,001.7	2,643.9
University-related agencies (≥300)	4	0	-----	-----	0	-----	-----	2	2,075.0	106.1
University-related agencies (<300)	10	0	-----	-----	2	100.0	113.1	4	66.7	57.9
Public social agencies (≥200)	2	1	2,082.0	0.0	2	1,000.0	1,060.1	1	3,969.0	0.0
Public social agencies (<200)	6	5	817.2	939.1	5	295.8	309.5	0	-----	-----
Local welfare depts. (≥100)	2	2	735.0	374.8	2	4,330.0	3,606.2	1	1,020.0	0.0
Local welfare depts. (<100)	4	3	108.7	89.0	4	343.7	320.0	0	-----	-----
Visiting nurse assns. (≥100)	1	0	-----	-----	0	-----	-----	0	-----	-----
Visiting nurse assns. (<100)	10	0	-----	-----	0	-----	-----	0	-----	-----

TABLE 16--Continued

Type Organization by Size (No. Employees)	N[a]	Patient/Client Records Cost ($100 Units) N[b]	Mean	SD[c]	Accounting Cost ($100 Units) N[b]	Mean	SD[c]	ADP Cost ($100 Units) N[b]	Mean	SD[c]
Private social agencies (≥ 50)	6	4	275.0	160.5	5	256.8	86.6	1	476.0	0.0
Private social agencies (< 50)	9	6	170.0	82.7	6	143.0	88.8	0	-----	-----
Nursing homes (≥ 50)	4	4	42.7	12.4	4	64.3	56.3	0	-----	-----
Nursing homes (< 50)	2	2	36.0	5.7	2	14.0	8.5	0	-----	-----
Mental health clinics (≥ 25)	8	6	91.8	84.1	7	130.9	101.9	3	41.0	30.1
Mental health clinics (< 25)	16	5	39.4	25.5	5	36.8	21.4	0	-----	-----
Local health depts. (≥ 25)	4	2	120.5	64.3	2	162.5	123.7	0	-----	-----
Local health depts. (< 25)	10	0	-----	-----	0	-----	-----	0	-----	-----
Registry/regulatory boards	7	1	830.0	0.0	3	88.3	18.9	2	1,007.5	767.2
State research/statistical units	4	0	-----	-----	0	-----	-----	0	-----	-----

[a]N refers to total number of organizations for which information was applicable.

[b]N refers to the total number of organizations for which information was available for computing the values reported.

[c]SD refers to standard deviations.

accounting with two exceptions--hospitals and one large local welfare department. In all likelihood, if these organizations had not had recourse to ADP, costs for patient or client records and accounting would have been much higher. Disproportionately large amounts of money were spent on ADP by planning and university-related agencies--undoubtedly attributable to large research enterprises therein. Standard deviations, again, indicate great variability between and within the various types of organizations studied.

Types of Equipment and Materials Used

A fifth question asked was: What types of equipment and materials are used? From the answer to this question, it is possible to infer the amount of machine-readable information available.

Complete data on the types of equipment and materials used in record keeping and processing were obtained on all organizations surveyed. McBee cards (tabulation cards employing marginal punches) were used by very few organizations--three larger hospitals, one smaller public social agency, and one visiting nurse association. A large proportion of the organizations in each category used keypunches and sorters. The exceptions were smaller hospitals, smaller local welfare departments, smaller visiting nurse associations, nursing homes, and local health departments. All university-related agencies, two of the three registry and regulatory boards,

and three of the four state research and statistical units used McBee cards.

To what extent have record keeping and processing been automated in health organizations and related agencies?

Reference has been made already to those organizations which have separate ADP departments and those which do not. (See Organizational Structure for Record Keeping and Processing.)

In additional, it was found that ADP was used exclusively for general purposes, that is, for both fiscal affairs and research, in half of the organizations using ADP. Almost all smaller planning agencies also used ADP for general purposes. University-related agencies, public social agencies, larger local welfare departments, larger visiting nurse associations, smaller private social agencies, mental health clinics, registry and regulatory boards, and state research and statistical units all fall into this category of use. Hospitals, especially smaller hospitals, tended to use ADP for fiscal purposes only. The smallest hospitals, local welfare departments, visiting nurse associations, and all nursing homes and local health departments made no use of ADP.

Computer usage was analyzed in the following ways: (1) by whether an in-house computer was used; (2) by whether staff initiated jobs on computers outside of the organization; or (3) by whether data were provided for computer processing to larger national or supervisory organizations by affiliates or local units. Hospitals, planning organizations, and university-related agencies

used computers more than any other type of organization. A fraction of the hospitals and many mental health clinics were subject to the requirement by supervisory organizations that they provide data for computer processing. The hospitals were primarily under Federal auspices, and the mental health clinics under state authority. Only one private social agency was subject to this requirement.

Few organizations had in-house computers. Though not apparent from Table 17, only the very largest hospitals, planning agencies, university-related agencies, public social agencies, and registry and regulatory boards could afford an in-house computer.

Staff-initiated applications on computers outside the organization were more prevalent. Planning organizations and university-related agencies were the largest users of computers by this definition. Two of the four state research and statistical units, two smaller public social agencies, two larger private social agencies, and three larger mental health clinics also made staff-initiated use of the computer.

Computers were not used at all by the smallest hospitals, the smaller local welfare departments, visiting nurse associations, nursing homes, and local health departments. The majority of registry and regulatory boards, private social agencies, smaller public social agencies, and medium-size hospitals made no use of the computer.

TABLE 17

TYPES OF EQUIPMENT, MATERIALS, AND USE IN RECORD KEEPING AND PROCESSING

Type Organization by Size (No. Employees)	N[a]	McBee Cards N[b]	McBee Cards % Using	Keypunch & Sorter % Using	Outside-Initiated Computer Application % Using	Staff-Initiated Computer Application % Using	In-House Computer % Having	General ADP N[c]	General ADP % Using
Hospitals (≥1,000)	9	9	11	89	22	22	44	9	33
Hospitals (500-999)	15	15	27	80	13	13	33	12	42
Hospitals (100-499)	24	22	0	32	9	14	9	9	11
Hospitals (<100)	6	6	0	0	0	0	0	0	---
Planning agencies (≥400)	7	7	0	86	0	29	29	6	33
Planning agencies (<400)	15	13	0	62	0	46	0	8	88
University-related agencies (≥300)	4	4	0	100	0	74	25	4	100
University-related agencies (<300)	10	10	0	100	0	90	10	10	100
Public social agencies (≥200)	2	2	0	50	0	0	50	1	100
Public social agencies (<200)	6	6	17	50	0	33	0	3	100
Local welfare depts. (≥100)	2	2	0	50	0	0	50	1	100
Local welfare depts. (<100)	4	4	0	0	0	0	0	0	---

TABLE 17--Continued

Type Organization by Size (No. Employees)	N[a]	McBee Cards N[b]	McBee Cards % Using	Keypunch & Sorter % Using	Outside-Initiated Computer Application % Using	Staff-Initiated Computer Application % Using	In-House Computer % Having	General ADP N[c]	General ADP % Using
Visiting nurse assns. (≥100)	1	1	100	100	0	0	0	1	100
Visiting nurse assns. (<100)	10	10	0	0	0	0	0	0	---
Private social agencies (≥50)	6	6	0	33	0	33	0	2	50
Private social agencies (<50)	9	9	0	11	11	0	0	1	100
Nursing homes (≥50)	4	4	0	0	0	0	0	0	---
Nursing homes (<50)	2	2	0	0	0	0	0	0	---
Mental health clinics (≥25)	8	8	0	63	25	38	0	5	100
Mental health clinics (<25)	16	15	0	60	60	0	0	9	100
Local health depts. (≥25)	4	4	0	0	0	0	0	0	---
Local health depts. (<25)	10	9	0	0	0	0	0	0	---
Registry/regulatory boards	7	3	0	67	0	0	33	2	100
State research/statistical units	4	4	0	75	0	50	0	3	100

[a]N refers to total number of organizations for which information was applicable.

[b]N refers to the total number of organizations for which information was available for computing the values reported.

[c]N in this column differs from N[b] because general ADP use applied only to organizations possessing ADP equipment and materials.

Total Record-Keeping and Processing Costs, Personnel, and Ratios

As expected, larger organizations incurred greater record-keeping and processing costs. As indicated by Table 18, ratios of record-keeping and processing costs to total budget varied greatly. Larger university-related agencies had the highest ratio--.552. They spent more than half their total budgets on record keeping and processing. Roughly one-quarter of local welfare department budgets and one-fifth of smaller university-related agency budgets and smaller public agency budgets were spent similarly. Hospitals, larger planning agencies, larger public social agencies, visiting nurse associations, nursing homes, mental health clinics, local health departments, and state research and statistical units all spent less than 10 percent of their total budgets on record keeping and processing. The ratio of record-keeping and processing costs of the latter group of organizations was related inversely to size; the larger the organization, the smaller the ratio. This relationship was most apparent among organizations of the same type.

Data on the average number of full-time record-keeping and processing personnel were less complete than costs. Available data support the expected finding: larger organizations employ more personnel in record-keeping and processing operations. Of organizations of various types and sizes, only smaller nursing homes employed no personnel for this purpose. The one larger

TABLE 18

RECORD-KEEPING AND PROCESSING COSTS, PERSONNEL, AND RATIOS

Type Organization by Size (No. Employees)	N[a]	Total Record-Keeping, Processing Costs ($100 Units)			Ratio of Record-Keeping, Processing Costs to Total Budget			Total Full-Time Record-Keeping, Processing Personnel			Ratio of Record-Keeping, Processing Personnel to Total Employees		
		N[b]	Mean	SD[c]	N[b]	Mean	SD[c]	N[b]	Mean	SD[c]	N[b]	Mean	SD[c]
Hospitals (≥1,000)	9	9	4,626.8	2,680.2	9	.04	.01	9	80.3	64.5	9	.04	.01
Hospitals (500-999)	15	15	2,158.1	875.6	15	.04	.01	15	34.6	11.9	15	.05	.01
Hospitals (100-499)	24	20	925.5	561.4	19	.04	.02	21	14.2	8.8	21	.05	.02
Hospitals (<100)	6	5	195.0	122.9	5	.06	.02	4	4.7	2.9	4	.11	.09
Planning agencies (≥400)	7	7	3,774.4	3,511.3	7	.04	.04	7	62.4	71.1	7	.06	.07
Planning agencies (<400)	15	13	801.6	1,356.0	13	.15	.14	11	7.6	6.5	11	.17	.13
University-related agencies (≥300)	4	4	9,998.0	0.0	4	.55	.16	1	183.0	0.0	1	.29	.00
University-related agencies (<300)	10	8	728.7	1,223.8	7	.20	.19	4	7.3	8.7	4	.21	.20
Public social agencies (≥200)	2	2	4,065.5	2,338.4	2	.04	.01	2	68.5	57.3	2	.04	.01
Public social agencies (<200)	6	6	1,117.2	1,096.3	6	.22	.30	6	19.0	19.3	6	.22	.26
Local welfare depts. (≥100)	2	2	6,015.0	5,324.5	2	.26	.08	2	103.0	67.9	2	.32	.24
Local welfare depts. (<100)	4	4	425.3	344.5	4	.29	.15	4	8.5	6.5	4	.36	.15

TABLE 18--Continued

Type Organization by Size (No. Employees)	N[a]	Total Record-Keeping, Processing Costs ($100 Units)			Ratio of Record-Keeping, Processing Costs to Total Budget			Total Full-Time Record-Keeping, Processing Personnel			Ratio of Record-Keeping, Processing Personnel to Total Employees		
		N[b]	Mean	SD[c]	N[b]	Mean	SD[c]	N[b]	Mean	SD[c]	N[b]	Mean	SD[c]
Visiting nurse assns. (≥100)	1	1	678.0	0.0	1	.06	.00	1	9.0	0.0	1	.06	.00
Visiting nurse assns. (< 100)	10	10	31.8	23.5	10	.09	.07	1	1.0	0.0	1	.11	.00
Private social agencies (≥50)	6	6	664.2	742.3	6	.10	.14	6	7.3	8.6	6	.11	.16
Private social agencies (< 50)	9	9	258.6	162.4	9	.15	.22	7	4.6	3.1	7	.24	.23
Nursing homes (≥50)	4	4	107.0	58.2	4	.04	.01	3	1.3	0.6	3	.02	.01
Nursing homes (< 50)	2	2	50.0	14.1	2	.02	.01	0	----	----	0	---	---
Mental health clinics (≥25)	8	8	205.0	159.5	8	.07	.03	5	2.8	2.5	5	.04	.02
Mental health clinics (< 25)	16	15	69.1	26.2	13	.09	.05	4	1.0	0.0	4	.09	.03
Local health depts. (≥25)	4	4	175.0	170.9	4	.05	.04	2	3.0	2.8	2	.06	.02
Local health depts. (< 25)	10	9	34.4	16.1	9	.06	.04	1	1.0	0.0	1	.10	.00
Registry/regulatory boards	7	3	1,099.0	672.3	3	.03	.04	3	11.3	3.8	3	.37	.55
State research/statistical units	4	4	1,222.7	562.1	4	.90	.15	4	15.7	5.1	4	1.00	.00

[a]N refers to total number of organizations for which information was applicable.

[b]N refers to the total number of organizations for which information was available for computing the values reported.

[c]SD refers to standard deviations.

university-related agency which provided information on full-time record-keeping and processing personnel reflected the high ratio of record-keeping and processing costs to total budget of organizations in this category. It reported 183 full-time employees in record keeping and processing. The larger local welfare departments ranked second in this regard. As for the remainder, the average number of full-time personnel in record keeping and processing ranged from one to 80. The smaller visiting nurse associations, mental health clinics, and local health departments each averaged one person.

The ratio of record-keeping and data-processing personnel to total employees varied from .000 to 1.00. All personnel in the state research ans statistical units were involved in record keeping and processing, yielding a 1.00 ratio. Local welfare departments ranked second with roughly one-third of total personnel in record keeping and processing. University-related agencies, smaller public social agencies, and smaller private social agencies had about one-quarter of their personnel in record keeping and processing. The ratios among other organizations were substantially lower. Larger nursing homes had a ratio of .019, while smaller nursing homes had a ratio of .000 since they did not employ record-keeping and processing personnel. Again, standard deviations indicate considerable variability within groups.

Policies Governing Release of Information

As a prelude to consideration of issues concerning confidentiality, the inquiry also asked: What are organizational policies and practices regarding release and sharing of information?

Organizations cited seven policies governing the release of information. Information can be released when: (1) it is authorized by the patient; (2) the person making the request is directly concerned (undefined); (3) an ad hoc decision (each case being judged on its own merits) has been reached; (4) it is authorized by statute; (5) it is a matter of public record; (6) it is anonymous; or (7) it is requested by an organization enjoying special exchange privileges. These data were available on all organizations surveyed.

Although organizations varied greatly in policies, some patterns of response were apparent. As shown by Table 19, most university-related agencies cited as their policy release of anonymous information only. One larger visiting nurse association and the smaller nursing homes stated a policy of sharing information only with persons directly concerned. The larger public social agencies claimed release of information was governed solely by statute.

The remaining organizations were more varied in policy. Most mental health clinics and half of all the hospitals (except the largest) indicated patient authorization was a necessary condition for the release of information. Most smaller visiting nurse associations, the larger nursing homes, half the largest

TABLE 19

POLICIES GOVERNING RELEASE OF INFORMATION

Type Organization by Size (No. Employees)	N[a]	Patient Authorization N[b]	Patient Authorization %	To Persons Directly Concerned %	Ad Hoc Decision %	Statute %	Public Record %	Anonymous Information %	Exchange Privileges %
Hospitals (≥ 1,000)	9	9	22	56	0	11	0	11	0
Hospitals (500-999)	15	15	53	20	0	0	0	27	0
Hospitals (100-499)	24	22	54	36	4	0	0	4	0
Hospitals (<100)	6	6	50	33	17	0	0	0	0
Planning agencies (≥400)	7	7	14	0	0	0	57	29	0
Planning agencies (< 400)	15	13	0	15	0	0	15	54	15
University-related agencies (≥300)	4	4	0	0	0	0	0	100	0
University-related agencies (<300)	10	10	0	0	40	0	0	60	0
Public social agencies (≥200)	2	2	0	0	0	100	0	0	0
Public social agencies (<200)	6	6	0	33	17	17	33	0	0
Local welfare depts. (≥100)	2	2	0	50	0	50	0	0	0
Local welfare depts. (<100)	4	4	25	0	0	50	0	25	0
Visiting nurse assns. (≥100)	1	1	0	100	0	0	0	0	0
Visiting nurse assns. (<100)	10	10	0	80	0	0	0	20	0

TABLE 19--Continued

Type Organization by Size (No. Employees)	N[a]	Patient Authorization N[b]	Patient Authorization %	To Persons Directly Concerned %	Ad Hoc Decision %	Statute %	Public Record %	Anonymous Information %	Exchange Privileges %
Private social agencies ($\geq$50)	6	6	17	17	0	0	17	50	0
Private social agencies ($<$50)	9	9	33	22	0	0	0	33	11
Nursing homes ($\geq$50)	4	4	0	75	0	0	0	25	0
Nursing homes ($<$50)	2	2	0	100	0	0	0	0	0
Mental health clinics ($\geq$25)	8	8	88	12	0	0	0	0	0
Mental health clinics ($<$25)	16	15	80	13	0	0	7	0	0
Local health depts. ($\geq$25)	4	4	25	0	0	0	25	50	0
Local health depts. ($<$25)	10	9	0	22	0	0	44	33	0
Registry/regulatory boards	7	3	0	0	0	0	67	33	0
State research/statistical units	4	4	0	25	0	0	0	75	0

[a]N refers to total number of organizations for which information was applicable.

[b]N refers to the total number of organizations for which information was available for computing the values reported.

hospitals, and the larger local welfare departments released information to persons directly concerned. Most smaller university-related agencies, the state research and statistical units, half the larger private social agencies, the smaller planning agencies, and the larger local health departments released anonymous information. Half the local welfare departments released information as required by statute.

The majority of registry and regulatory boards, half the larger planning agencies, and the smaller local health departments cited release of information considered a matter of public record. Release of information to organizations enjoying special exchange privileges or based on ad hoc decisions were policies cited in but a few instances. Four of 10 university-related agencies made ad hoc decisions.

In actuality, there may be little difference between the various policies governing the release of information. Possible exceptions are matters of public record and release of information to agencies having special exchange privileges. Release to persons directly concerned and ad hoc decisions seem to permit professionals and organizational representatives greater latitude in reaching a decision than rigid adherence to the policy of patient authorization. Patients are not always apprised of their condition, and free flow of information among professionals cannot always wait for patient authorization. Undoubtedly, many administrators and professionals interpret statutory provisions regulating release

of information in ways which support these policies and the practices in the field. The policy of releasing information anonymously complements all of these policies.

Release of information which is part of the public record was cited most frequently by governmental agencies. This information tends, in most instances, to be qualitatively different from information governed by the other policies, although some items in the public record, such as court appearances and individual birth, marriage, and death data, are kept confidential unless requested from agencies charged with responsibility for their release.

Of 79 organizations making reference to secondary policies governing the release of information, 24 (30.4%) cited release to persons directly concerned; 21 (26.6%), ad hoc decison making; and 19 (24.0%), release of anonymous information. The remainder made reference to (1) policies of patient authorization (11.4%) or (2) release of information in the public record (7.6%). Responses to the question of policies governing the release of information cluster around highly complementary themes--release to persons directly concerned, ad hoc decision making, and release of anonymous information. They tend to support the proposition that, actually, only slight differences may exist between ostensively different policies.

Request for Annual Report

As shown in Table 20, the majority of organizations submitted copies of their most recent annual report. The request evoked a 100 percent response from larger public social agencies, smaller local welfare departments, larger visiting nurse associations, and the larger local health departments. State research and statistical units responded with equivalent substitute materials. Only a handful of organizations refused to send or promised but did not send an annual report. Another group of organizations, however, claimed that they had no annual report to give. Considering the statutory requirement that every incorporated organization submit an annual financial statement to the office of the secretary of state, this claim was surprising. It might be interpreted as one way of blocking access to information about corporate affairs when the inquirer's intentions are unknown. Two-thirds of the smallest hospitals, the majority of nursing homes, almost half the largest hospitals, and four of the 10 smaller university-related agencies claimed they had no annual report. The number of hospitals of every size without an annual report to send was unexpected. Similarly, the refusal or claim of no report by 50 percent of the larger private social agencies was surprising.

Overall Relationships

Another question to which an answer was sought was: What are the similarities and differences among organizations of

TABLE 20

REQUEST FOR ANNUAL REPORT

Type Organization by Size (No. Employees)	N[a]	Sent N[b]	Sent %	Substitute Sent %	None to Send %	Promised But Not Sent %	Refused %
Hospitals (≥1,000)	9	9	56	0	44	0	0
Hospitals (500-999)	15	15	73	0	27	0	0
Hospitals (100-499)	24	22	50	4	32	0	14
Hospitals (< 100)	6	6	33	0	67	0	0
Planning agencies (≥400)	7	7	43	29	29	0	0
Planning agencies (<400)	15	13	69	38	15	0	0
University-related agencies (≥300)	4	4	75	0	25	0	0
University-related agencies (< 300)	10	10	30	20	40	0	10
Public social agencies (≥200)	2	2	100	0	0	0	0
Public social agencies (< 200)	6	6	67	0	33	0	0
Local welfare depts. (≥100)	2	2	50	0	50	0	0
Local welfare depts. (< 100)	4	4	100	0	0	0	0
Visiting nurse assns. (≥100)	1	1	100	0	0	0	0
Visiting nurse assns. (< 100)	10	10	60	0	20	10	10

TABLE 20--Continued

Type Organization by Size (No. Employees)	N[a]	Sent N[b]	Sent %	Substitute Sent %	None to Send %	Promised But Not Sent %	Refused %
Private social agencies (≥100)	6	6	50	0	33	0	17
Private social agencies (<100)	9	9	67	0	22	11	0
Nursing homes (≥50)	4	4	0	0	50	25	25
Nursing homes (<50)	2	2	0	0	100	0	0
Mental health clinics (≥25)	8	8	88	0	12	0	0
Mental health clinics (<25)	16	15	40	0	40	13	7
Local health depts. (≥25)	4	4	100	0	0	0	0
Local health depts. (<25)	10	9	67	0	33	0	0
Registry/regulatory boards	7	3	67	0	33	0	0
State research/statistical units	4	4	50	50	0	0	0

[a]N refers to total number of organizations for which information was applicable.

[b]N refers to the total number of organizations for which information was available for computing the values reported.

different types and sizes on the various questions this inquiry has been posing?

Correlational analysis disclosed a number of significant relationships between study variables.[7] These relationships abstract from the types of organizations involved. As expected, larger organizations had larger budgets (.92), incurred greater costs for record keeping and processing (.71), and generally served greater numbers of patients or clients (.25). Larger organizations more often than smaller ones tended to use computers (.29). The largest organizations had computers in-house (.49).

Larger organizations with in-house computers tended to have separate departments for patient or client records (.26), accounting

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[7]Linearity of relationships between study variables was assumed, and Pearsonian correlation coefficients calculated accordingly. In view of limited funds for statistical analysis and the small sample size, tests of curvilinearity did not appear warranted.

In most instances, interval data justified the use of the Pearsonian r. Nominal data were reduced to dichotomies (the least interval scale) before calculation. This practice is heuristic yet customary among statisticians--especially in regression analysis using dummy variables.

Correlation coefficients were considered significant if they could have occurred by chance less than 5 times in 100. Only significant correlations between variables are presented in the text.

The correlation coefficients indicate the strength of significant relationships on a continuum ranging from zero (no relationship) to plus or minus 1 (perfect positive or negative relationship). Although many coefficients reported indicate weak to moderate relationships, they do support affirmative statements about significant relationships between variables--so long as it is understood that such relationships could have occurred spuriously 5 times or less in 100. There are no theoretical reasons why any of the relationships reported as significant should have been any stronger or weaker than they appear. The purpose of the analysis was to explore possible relationships--not to test exact hypotheses.

(.36), and ADP (.66), to use ADP for fiscal purposes only (.23), to follow statutory provisions in sharing information (.19), and to submit an annual report upon request (.18). Organizations with staff-initiated computer applications were likely to have a research department (.27), larger data-processing costs to total budget ratio (.24), greater numbers of part-time personnel (.35), and a policy of releasing anonymous information (.26). Organizations using computers because of external requirements to supply data for computer processing tended to fall under Federal auspices (.38), to share information only if authorized by the patient or client (.29), and to promise but send no annual report (.16). Organizations which made no use of computers differed somewhat from the rest. They tended to fall under municipal (.21) or proprietary (.20) auspices; to lack separate departments for accounting (.18), ADP (.33), or research (.22); and to share information about patients or clients with those directly concerned (.20).

In general, organizations with separate record-keeping and processing departments shared characteristics common to larger organizations. However, there were a few differences dependent upon the type of department involved. Organizations with patient or client record departments generally had a policy of sharing information when authorized by patients or clients (.17). Organizations with accounting departments were apt to have an associated ADP department (.26), but they had no characteristic policy governing the release of information. Organizations with research departments,

as stated above, were apt to use computers on staff initiative and to have a high ratio of data-processing costs to total budget. They also tended to fall under state auspices (.22), to follow statutory provisions in releasing information (.15), and, when requested to send an annual report, to send substitute materials (.20).

Organizations which used ADP for general rather than solely fiscal purposes employed fewer persons in accounting (.38), had smaller budgets (.41), and, in general, spent less for record keeping and processing (.32). They were likely to be smaller organizations (.47) under state auspices (.25) with neither a department for patient or client records (.58) nor for accounting (.66).

The relationship of organizational auspices to use of equipment, policies governing release of information, and, to a minor extent, the reaction to the request for a copy of the annual report, although reflected in the findings above, deserves restatement and focus. Organizations under Federal auspices tended to make indirect use of computers; that is, the government required that they supply data on forms designed to facilitate computer processing (.38). Fiscal purposes dominated in the use of ADP (.24). Organizations under state auspices tended to share information according to statutory provisions (.17) or on a matter of public record (.28). Organizations under municipal auspices largely used ADP for fiscal purposes only (.31) and made no use of computers (.21).

Voluntary, nonprofit organizations made greater use of computers (.26) and relied upon patient authorization as the rule governing release of information (.31). Proprietary organizations tended not to use computers (.21), to share information only with those directly concerned (.19), and to ignore the request for an annual report (.39).

Summary and Conclusions

The current revolution in data processing has raised many questions concerning the impact of automation upon health organizations and related agencies in Metropolitan Boston.

To discover what the present situation is in this field and to learn whether these groups are willing and able to participate in a computer-based health and welfare information network, the inquiry undertook--as a first step--an inventory of record keeping and processing within relevant organizations.

A number of questions were asked in order to gain needed information. Primary areas of inquiry were: the organizational structures which had evolved for processing data; manpower employed; costs involved; types of equipment and material used; the extent to which record keeping and processing have been automated; and policies governing release of information.

This inventory was expected to give an overview of the field, to assist planners in judging how much machine-readable data were available for immediate storage and use, and how ready organizations of various types and sizes might be, technically, to make the

transition to information sharing via the computer. Similarities and differences on these issues might suggest which organizations were suited for linkage into subsystems before ultimate coupling to a community-wide health and welfare information system, if such an undertaking appeared worthy of pursuit.

The inventory also was expected to yield information on the relative size and importance of organizations from the standpoints of (1) service to large segments of the population; (2) potential influence by virtue of financial resources; and (3) degree of expertise in record keeping and processing. Decisions on which health and related organizations to approach for closer study were based on this information.

From the standpoint of resources, specialized structure, and expertise in use of ADP and/or the computer for record keeping and processing, larger and medium-size hospitals, planning organizations, registry and regulatory boards, state research and statistical units, and university-related agencies appear most ready to make the transition to information sharing via the computer.[8] They also have machine-readable data, although the amount of data relevant requires clarification.

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[8]Readiness, however, should not be interpreted as willingness. It is a moot question whether readiness in terms of resources, specialization, expertise, or even common needs for health-related information can be translated into coordinated activity. Relative autonomy and self-sufficiency might encourage "going it alone." Smaller, less-endowed organizations, on the other hand, might find it advantageous to pool resources and efforts in order to achieve ADP capabilities beyond their separate abilities.

Similarly, these organizations have many common needs for health-related information--whether for purposes of administrative and/or inter-organizational planning, public accountability, supervision, and control functions or for epidemiological and operational research. With few exceptions, these organizations had the largest annual budgets, spent the most money on record keeping and processing, and employed the greatest number of full- and part-time people in individual records, accounting, and ADP. They had greater access to in-house computers and/or made more staff-initiated applications of the computer than the other organizations.

It is important to realize, however, that this group of organizations enjoys only relative superiority in use of ADP and/or the computer in record keeping and processing. Expressed in absolute numbers, four of the nine largest hospitals had an in-house computer, four an ADP department, and two made staff-initiated applications of a computer located outside of the institution. Of the 37 medium-size hospitals, seven had an in-house computer, four an ADP department, and five made staff-initiated applications of a computer.

Two of 20 planning agencies had an in-house computer, three an ADP department, and eight used computers on staff initiative. Of 14 university-related agencies, two had in-house computers, none had a separate ADP department, and 12 made staff-initiated applications of a computer. The combination of four state research and

statistical units and three registry and regulatory boards had one in-house computer, two ADP departments, and two staff-initiated applications of a computer.

The majority of all these organizations used keypunch and sorting equipment, thereby generating machine-readable data of some kind.

Viewed in absolute terms, then, the relative superiority or expertise in use of ADP and/or the computer enjoyed by larger and medium-size hospitals, planning organizations, registry and regulatory boards, state research and statistical units, and university-related agencies does not indicate that the contemporary revolution in data processing has had a very large impact upon these groups. It implies virtually no impact upon the majority of other types of organizations surveyed--public social agencies, local welfare departments, visiting nurse associations, private social agencies, nursing homes, local health departments, and mental health clinics.

Neither the analyses of differences between organizations of different types and sizes nor correlational analyses abstracting from organizational types revealed groups of organizations naturally suited for linkage into subsystems before ultimate coupling to a community-wide health and welfare information system.

Organizational size tended to explain the largest proportion of variance on almost every issue. Larger organizations incurred greater costs for record keeping and processing, tended to use a computer (either in-house or off the premises), concentrated record-

keeping and processing operations into specialized departments, followed statutory provisions in sharing information, and gave evidence of greater responsiveness to requests from the outside for information.

Missing from the profile of the larger organizations was some unifying auspices, a standard policy for releasing information (the strength of the relationship between size and release according to statutory provisions was weak--.19), and a tradition of compacts or special agreements facilitating exchange of information between agencies. The missing elements are assumed to be important criteria for identifying groups of organizations naturally suited for linkage into subsystems.

CHAPTER VI

GENERAL INTRODUCTION TO VIGNETTES OF SELECTED HEALTH AND WELFARE INFORMATION SYSTEMS

Information systems within nine health organizations and related agencies in Metropolitan Boston were selected for study in greater depth.

Criteria which guided choice of these organizations were: (1) importance because of organizational size and proportion of population for which they are responsible, either as direct-service or data-processing agencies; (2) leadership potential and influence; (3) executive or lower echelon interest in a community-wide information linkage system; and (4) experience in modern techniques of data processing.

These selection criteria and one other--representativeness--were approved on August 15, 1967, by the Joint Center Health Information System Advisory Committee. On December 21, 1967, the Committee approved the nine organizations selected according to the criteria. There was no way by which all five criteria could be applied with equal weight in deriving a sample of nine or 10 organizations from the universe of relevant organizations in Metropolitan Boston.

Although it is usually desirable to achieve statistical representativeness in surveys of any kind, limited staff resources, the exploratory character of the study, and some precedent in computer literature for emphasizing experience in modern techniques of data processing made adherence to the criterion of representativeness appear less critical than usual. Since most information for managerial decision making and planning has become available as a spin-off from systems devised for what has been called "bread and butter" data processing, experience in modern techniques of data processing appears most critical if the goal is to establish community-wide linkages of health and welfare information.[1]

The nine organizations selected for in-depth study were: (1) New England Medical Center Hospitals, (2) Children's Hospital Medical Center, (3) Associated Catholic Hospitals, (4) Massachusetts

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[1] See, for example, James R. Zeigler, Time-Sharing Data Processing Systems (Englewood Cliffs, N.J.: Prentice-Hall, Inc., 1967), p. 29 and Perry E. Rosove, Developing A Computer-Based Information System (New York: Wiley and Sons, 1967) pp. 13-16. To date, "bread and butter" operations alone have justified the considerable outlay of capital for equipment and personnel necessary for on-going batch or on-line computer systems. The critical importance of experience in modern techniques of data processing is highlighted by the findings in chapter V of this report. Larger organizations with greater budgetary resources, manpower, and responsibility for large segments of the population spend the most on record keeping and processing and make use of ADP and computers more than the rest. They have reason to acquire and to make machine-readable information which could be linked in a community-wide health and welfare information system. In essence, all selection criteria except representativeness converge. At the same time, limited resources did not permit closer study of all organizations meeting the criteria accepted as primary in the present context.

General Hospital,[2] (5) Boston Department of Health and Hospitals, (6) State Department of Public Health, (7) State Department of Public Welfare, (8) Massachusetts Blue Cross-Blue Shield, and (9) United Community Services of Metropolitan Boston.

Within each organization one or more related information systems were subjected to review and analysis. This phase of study had a number of linked objectives, all calculated to permit evaluation of the reliability and availability of existing data for community-wide sharing and use. More specifically, the following groups of questions guided review and analysis of the information systems studied.[3]

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[2]This report does not present complete findings on Massachusetts General Hospital. The focus of in-depth study at MGH was to have been a computerized medical records control system, developed by MGH in collaboration with Wesco, a computer consulting firm. MGH executives have been in the process of getting the system operable. During the transitional phase, they requested that Medical Foundation staff not review the system. When it was ready for review, the Medical Foundation was assured of full cooperation and assistance. As it happened, the system at MGH never became operable in time for review and presentation in this report.

MGH executives have responded, nevertheless, to the query about their ability and willingness to participate in a computer-based community-wide health and welfare information system. They feel that numerous obstacles dictate nonparticipation in development of such a system at this time. They believe, for example, that the size and number of their medical records make it impractical to collect abstracts for an archive. Individualized data on hospital employees are considered confidential within the institution. Budgetary and operational data on programs for all services are at present made available only to Blue Cross and the Commonwealth of Massachusetts. Although unable to participate, MGH executives do not wish to discourage efforts of others. In fact, they feel that they may be more suitable candidates for participation when they have progressed further in developing their own internal information systems.

[3]See Appendix E for copy of Record Management Interview Guide.

Data Collection

---- What information is now gathered?

---- What definitions (conventions) guide collection?

---- Who actually completes the forms used?

---- At what stages of service to patients or clients is information gathered?

Data Processing and Storage

---- What checks are taken to verify accuracy and completeness of the data?

---- What are the stages and types of filing employed?

---- How are the data analyzed and can the findings be generalized?

---- Where, in what form, and for how long is the collected information stored?

Usage--and Needs for Additional Information

---- Under what conditions is the record used and by whom?

---- Where is information summarized in reports?

---- What additional information, if any, do administrators and planners within the organization need, particularly with respect to the system studied?

---- How much additional information sought must come from outside sources?

---- How is additional information currently obtained?

Problems--and Plans for the Future

---- What problems confront the staff in implementing the existing information system?

---- What plans exist for modifying the system?

Executive Response to Proposed Information System

---- What types of information do executives say they can share if a health and welfare information system of one form or another is initiated?

---- What preferences do executives have with respect to:

(a) A directory of information, stored in various agencies, which could be made available to authorized persons?

(b) A central registry or exchange identifying patients and clients on whom additional information could be obtained by contacting the organizations serving them?

(c) An archive in which are stored abstracts of health, welfare, and social agency records on individuals served?

---- Under what auspices do the exeuctives think a computer-based health and welfare information system serving Metropolitan Boston could best be developed?

The chapters which follow present vignettes of the organizations chosen for in-depth study, summarizing their situation and position on the above questions.

CHAPTER VII

OUTPATIENT AND EMERGENCY CLINIC RECORD SYSTEM OF THE NEW ENGLAND MEDICAL CENTER HOSPITALS

Introduction

In 1966, New England Medical Center Hospitals spent $10,452,891 in the care of 10,244 inpatients and in providing outpatient services to patients who made 96,974 visits. The Center received $4,721,923 in research grant awards. Personnel numbered 1,900. A total of $996,391 was spent in five departments concerned with record keeping and processing. The five departments--general accounting, credit, medical records, personnel, and ADP systems--employed approximately 97 persons. The ADP systems department alone employed 17 persons and cost $243,609 to maintain. It had on-premise use of the IBM 360-30 computer with card processing peripheral equipment. The Center is an institution which has successfully integrated diverse organizations and/or functions into a coordinated whole. At present, New England Medical Center Hospitals is undertaking a $72.5 million development program. Decisions for expansion will rely, in part, upon an integrated data base under development, reflecting the major activities of the hospital complex.

Review of the system of maintaining and processing outpatient and emergency clinic records at New England Medical Center Hospitals provides an opportunity to assess the situation now confronting hospital administrators as they attempt to use outpatient and emergency clinic data for rational planning. Study of the existing system may also suggest directions for improvement and, possibly, expansion.

Outpatient services are provided in all four units comprising the New England Medical Center Hospitals complex. They include 20 outpatient clinics of the Boston Dispensary, which is entirely an outpatient operation; the outpatient clinics of the Rehabilitation Institute; the pediatric ambulatory clinics and private office practice of the Boston Floating Hospital for Infants and Children (pediatric unit); and the Pratt Diagnostic Clinic and private office practice of the New England Center Hospital (adult unit). Emergency services are provided in two locations: at the emergency clinic on an around-the-clock basis and in the pediatric ambulatory clinics during clinic hours.

Information gathered in the outpatient and emergency clinics varies somewhat in detail and collection procedure. Essentially, it consists of medical records[1] with identifying, admission, and diagnositic and/or treatment information (including laboratory and X-ray reports) on every individual served, as well as monthly

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[1]The terms medical records and patient records are used interchangeably in this report.

service statistics on the number of visits by new or revisit status and type of service. More specifically, identifying and admission information collected includes name; address; telephone number; age; sex; birth date; marital status; name, address, and telephone number of spouse, parent, relative, or friend; religion; occupation; employer; employer's address; allergy status; name and address of doctor to whom any medical report is to be sent; and hospital insurance coverage--whether Blue Cross, Blue Shield, or other coverage. The service statistics compiled are described in detail as they apply to particular operations.

Information is gathered at various stages of patient processing. Forms used in the collection of medical record information include an admission sheet and a diagnosis sheet for each unit or, in the case of emergency clinics, an emergency record. In addition, at the Boston Dispensary, a financial card form is used to obtain supplementary admission information on payment status as it relates, for example, to the number of dependent children, take-home pay, mortgage or rent payments, and third-party payments.[2] Service statistics for the 20 outpatient clinics of the Boston Dispensary, the pediatric ambulatory clinics, the Pratt Diagnostic Clinic, the private office practices, and the emergency clinic and pediatric emergency services are collected on statistical worksheets applying to particular service areas.

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[2]The financial cards are numerically filed by terminal digit numbers and are kept for 3 years in the active file and 5 years in the inactive file in the Boston Dispensary admission area.

Identifying and other information related to admission is recorded by the admission officer or other person responsible for this function. Information on diagnosis and/or treatment is recorded by the attending physician. Service statistics worksheets are completed by the clerk or nurse responsible for receiving patients in the service area. Information collection is such an integral part of the service routine that it does not require special training beyond the initial job orientation.

Medical Records

Medical record information is contained in a medical record folder, identified by patient unit number. Patient unit numbers are assigned to every individual served. Reference to patient by name and unit number in the medical record index permits determination of whether an individual has ever been served by any unit within the hospital complex. The first step in patient processing is, therefore, a check to determine whether a medical record on the patient exists. The admission area is responsible for checking with the medical record room[3] for a possible medical record. If none exists, a medical record is created. Medical record folders with pre-assigned patient unit numbers are available for this purpose.

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[3]Currently, there are actually 2 medical record rooms: one for the Boston Dispensary, Rehabilitation Institute, and Floating Hospital records; the other for the Pratt Clinic-New England Center Hospital. It represents a dual record system with different patient unit number assignments, although provisional numbers conforming to those assigned in the combined Boston Dispensary-Floating Hospital record system are being assigned to the New England Center Hospital records in preparation for their integration into a centralized record room in the near future.

The medical record, whether newly created in the admission area or located in the record room, is sent to the service area and, after use, returned to the medical record room. Medical records of patients undergoing continuing short-term diagnostic workup are sometimes temporarily kept in the Pratt Diagnostic Clinic and, in the case of private office practice, in the physician's office, with only a receipt for the medical record file in the medical record room.

Medical records, filed by terminal digit number, are stored in their original form in the record room for 10 years. Then the discharge summary is microfilmed. In total, medical records are kept for 55 years, the length of time required by statute. Records can be recalled and activated any time a patient receives service. The information contained in the medical record is used for clinical research by doctors, nurses, medical students, and authorized outside agencies. Requests for medical record information on patients are made by lawyers and doctors and by rehabilitation, welfare, and other agencies. The patient's authorization, however, must always be obtained for release of information.

Medical record discharge summaries of Pratt Diagnostic Clinic patients are the only outpatient data machine processed. The nature of the service rendered--diagnostic and non-continuous--makes medical records of Pratt Diagnostic Clinic patients suitable for machine processing, along with inpatient discharge records.[4]

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[4]It was emphasized that processing of data for other types

Discharge summaries are prepared for machine processing in the medical record room. To exert control over processing, a system for dating various stages of recording has been instituted. It includes maintaining a daily record of admitted and discharged patients by name, floor number, and physician. Similarly, the date on which the physician dictated a medical summary and the date on which it was typed, mailed to another physician, and finally received in the medical record room are noted. There is no provision for checking on missing or incorrect information in the medical record entries.

Individual discharge summaries are coded by patient number, age, sex, discharge date, type of service, whether the patient died, clinical diagnosis/complication, operation and physician, pathological diagnosis, and X-ray diagnosis. Pathological diagnosis and X-ray diagnosis[5] are precoded by the physician dictating the discharge summary. Medical record coding clerks, who receive intensive inservice training, code clinical diagnoses and surgical procedures according to the International Classification of Diseases, Adapted. They record information concerning the physician and hospital service by reference to a coding manual. In a separate procedure, which serves to check on the accuracy of

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of outpatient service does not appear to be feasible, given the generally continuous nature of outpatient services.

[5]The X-ray diagnosis is coded according to the American College of Radiology Code.

these coded items, the information is transferred to the medical record coding sheet.

The data processing department then processes medical record discharge information and stores it in disk memory form. This information has been coded since January 1966 for use principally in clinical research. Print-outs have been generated but, to date, the data have not undergone analysis because clinical researchers require data for a longer time period.

Service Statistics

Service statistics are gathered from the various service areas, including each of the 20 clinics in the Boston Dispensary. They are derived from the record log of each service area, in which date, name, patient unit number, fee(s), and visit status (new or revisit) are entered for each patient. Visit status is determined by checking whether a patient unit number has been previously assigned or whether entries on the medical record have been made by other services. The latter is characteristic of clinics of the Boston Dispensary. They report visits not only as new or a revisit to the Boston Dispensary but also as new or a revisit to the particular clinic. Record log entries are tallied and reported on the monthly statistical worksheet. For the 20 clinics of the Boston Dispensary, weekly tallies are kept.

Service statistics for Boston Dispensary clinics and the

Rehabilitation Institute are also produced at the cashier section of these service areas.[6] This is essentially a control process undertaken as a check on the independent statistics of Boston Dispensary clinics and for preparation of bills. A daily cross-check of money and service counts is made by reference to the cashier's report form and register roll of charges and payments for each clinic by payment classification; that is, whether private, Medicare, other agency payment, free, or health services to hospital employees. The person responsible for this check also keeps a card listing Rehabilitation Institute outpatients by service and amount owed. Thus, it is possible to determine the number of individuals as well as visits to the Rehabilitation Institute.

Statistics for ancillary services such as laboratory and X-ray tests are handled in a separate procedure in the accounting department. Outpatient, laboratory, and X-ray requisition slips are sorted and categorized by department, and patient service class (ambulatory, emergency, private or semi-private, and ward). They are then sent to an outside computer service for processing, at which time the number of tests, films, and other procedures per requisition are punched on cards. Outpatient and inpatient slips (prepared by the ADP systems department) are sent to the outside service bureau for merging and generation of print-outs for monthly reports of statistics on ancillary services.

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[6]The operation of the Boston Dispensary clinics differs from the other outpatient services in that patients must go to the cashier prior to the clinics.

Service statistics collected from each service area are compiled by the accounting department and noted in a monthly statistical report which summarizes service activity for the entire hospital for the month and, on a cumulative basis, for the current and past fiscal year. Service statistics sheets are due from each service area by the 10th day of the following month, and checks are made on delivery by means of control sheets listing data received or due. Boston Dispensary clinic activities, for which statistics are collected by both the clinics and the cashier control section, are cross-checked by reference to the independent sources of information.

Aggregate service data with a focus on visits is reported for each of the four outpatient areas of service. New patient visits and revisits are reported for the Pratt Diagnostic Clinic, the pediatric clinics, and the private professional practice of the adult and pediatric units. Also reported for the pediatric unit are total pediatric clinic visits by specific type of service, the number of pediatric emergency clinic visits, and the total number of patients admitted for inpatient service from the pediatric clinics and emergency service.

The Rehabilitation Institute service data include the total number of individual outpatients, number of visits, and number of outpatients given psychological testing, rehabilitation counseling, and dental treatments. The Boston Dispensary reports total visits by type of clinic and payment status (private, Medicare, other

agency payment, free, or health services to hospital employees). It is evident from the foregoing that with the exception of new patients and the Rehabilitation Institute's tabulation of individuals, the emphasis in rendering service statistics is upon visits.

Monthly statistical reports are typed and Xeroxed for internal distribution to department administrators and planners. Summary data of outpatient and emergency visits are published in an annual report. Service statistics are collected for administrative needs, for meeting licensing and accreditation requirements, and for reports to outside agencies such as United Community Services. More refined breakdowns of service statistics than those reported in the monthly statistical report are available to the administrators in charge of the various areas from the statistical worksheets. The statistical worksheet for the Boston Floating Hospital (pediatric unit), for example, not only includes the information mentioned but also contains information on the number of new and followup patients with birth defects. The administrator responsible for Boston Dispensary clinics collects information from each clinic on the number of new patients and revisits, new patients to the Dispensary, and number of employees served each week, as well as the number of visits in the form of consultations, emergencies, or special procedures. Emergency service statistics give a daily breakdown of the number of child or adult visits by hour and the number of corresponding house admissions. In addition, the planning division currently collects supplementary information on the number

of visits by type of service rendered by private professional services. This information is obtained from the ledger sheet maintained in the accounting department for each physician in the private professional service.

Problems

The whole outpatient information system, a slow manual operation, is cumbersome. The same type of information has been collected for many years. Administrators in charge feel the system needs evaluation and updating to meet current demands. The shortage of adequately trained medical transcribers and coding clerks is viewed by the medical record librarian as endemic to medical record departments in general. It affects, in particular, medical discharge processing.

Additional Information Needed

Administrators and planners at New England Medical Center Hospitals desire additional information on the use of outpatient services as related to factors of supply and demand in the hospital and in the entire community. High-priority items are information on clinic use by persons living at varying distances and data on inter-hospital patterns of outpatient visits by persons living in specific geographic areas. Data on the sociological characteristics of the population at risk are considered essential for planning the types of service most required. In addition, since the hospital is frequently confronted with the problem of in-

patient overload, information on bed availability in other hospitals would make referrals easier. This also applies to the emergency services and to the outpatient clinics (to the extent that need for inpatient care changes outpatient status).

At present, no information is obtained from outside sources relating specifically to the outpatient (and emergency service) populations of the hospital complex. Administrators and planners consult general studies conducted by various outside groups when needed. One such study described the characteristics of the population at Columbia Point. Another study in process is the Castle Square and South Cove Comprehensive Medical Needs Survey, a house census survey. This survey collects identifying information such as name, age, sex, race, and other characteristics as well as medical needs and financial information.

Plans for Improvement

At the time of review, the dual medical records system was to have been consolidated and centralized within three to four months. Plans were to review and revamp the entire statistical system.

A centralized ambulatory system and central diagnostic area serving all patients is expected to be in operation by 1970-1971. The plans call for a computerized outpatient system, with capabilities for central booking of appointments, generation of charge tickets and requisitions for tests, and pre-programmed results of tests in the central diagnostic area by means of a 13- to 14-channel

auto-analyzer tied into the digital computer. The plans also include scheduling inpatient admissions according to bed availability and operation times.

Ability and Willingness to Participate in a Community-Wide Information System

New England Medical Center Hospitals has been conducting a rather comprehensive study on the feasibility of developing a Department of Health Information Services which would link the hospital information system to academic computing facilities at Tufts University and elsewhere. Center administrators have reviewed nearly every computer project located in comparable medical centers throughout the country. They conclude that there is much potential both in the development of an integrated computer-based information system and in the development of medical school curricula giving students broader exposure to computer scientists and to the health information sciences. New England Medical Center Hospitals hopes to establish linkage with any regional computer-based information system storing data on medical records and regional utilization statistics. The Center has already investigated the possibility of linkage to MEDLARS (Medical Literature Analysis and Retrieval System) and Project MAC (Multiple-Access Computer System) for library access.

Although enthusiasm for possible access to a regional data base is high, there were some reservations about participation. New England Medical Center Hospitals would be interested in participating in a regional system if an organization ruling on the handling

of confidential or proprietary information could be obtained and if the usefulness of the system to both medical staff and administrators was clearly demonstrated. New England Medical Center Hospitals would become an "enthusiastic user and supporter" if a system were developed which was (1) easily accessible, e.g., by a remote terminal located in the medical record department, and (2) carefully enough planned to become self-sufficient and free of significant political harassment.

New England Medical Center Hospitals could contribute any information which has already been rendered machine-readable and which organizational policy has not declared proprietary or confidential. No decision has been rendered by administration, however, on an exact policy governing the release of data to a regional system. If and when a system is under design and development, clarification on policy freeing information for regional use will be made.

It was felt that a system serving Metropolitan Boston should be government-funded in its developmental stages. Later, users can assume the cost of maintaining the system. Financial support by users at the outset was deemed unfeasible because actual utility cannot be judged until computer techniques for managing the data base have been perfected and terminals installed. There was cautious optimism about obtaining significant financial support from users. It would depend upon establishing a properly designed system--an extremely important contingency.

CHAPTER VIII

COMPUTERIZED OUTPATIENT AND EMERGENCY CLINIC INFORMATION SYSTEM OF THE CHILDREN'S HOSPITAL MEDICAL CENTER

Introduction

Children's Hospital Medical Center represents an integrated complex of organizations and functions. In 1966, it spent $12,544,257 in the care of 12,008 inpatients and in providing outpatient services to patients making 149,098 visits. It received $3,846,409 in research and educational grant awards. Personnel numbered 1,300. A total of $1,132,778 was spent in three departments devoted to record keeping and processing. The three departments--medical records, accounting, and data processing--employed 177 persons. The data processing department employed 21 persons and cost $287,000 to maintain. It is in process of changing from the IBM 360-30 computer to the Honeywell 1200. A variety of peripheral and on-line equipment is employed in operation of two major hospital information systems. Progress to date in automating hospital functions includes development of on-line systems for maintaining a bed inventory and for scheduling appointments in outpatient and emergency clinics. Study of the computerized out-

patient and emergency clinic information system provides some contrast to the manual system in operation at New England Medical Center Hospitals.

The outpatient and emergency clinic information system of the Children's Hospital Medical Center has been developed under a three-year Federal demonstration grant. Initiation of the computerized on-line system for appointment scheduling and data retrieval has entailed creation within computer memory of a patient index locater file on every outpatient served. Input-output terminals in the registration area are used to make direct entries into computer memory. Typical entries include the scheduling of appointments, admission of new patients, updating of records and clinic notes, and the changing of clinic titles. The on-line system is currently limited to 44 of the 54 clinics of the outpatient department. Emergency department clinics will be phased into the system during the summer of 1968. This report describes the current system for managing medical and statistical data collected in the outpatient and emergency department clinics.

Information collected in the outpatient and emergency clinics includes identifying, admission, and diagnostic data comprising the patient medical record, service statistics on the number of patient visits, and information on clinic attendance. Identifying information consists of standard name, address, sex, age, date of birth, birthplace, religion, and marital status. Admission and diagnostic data include parents' names, address(es), occupation and employer,

name and address of nearest relative, family doctor, referring doctor or agency, private staff doctor, payment status (insurance or third-party payer), admitting clinic and date of admission, and diagnoses, operations, and results of any tests or examinations. Service statistics comprise the number of patient visits by new or revisit status and by type of referral to each outpatient clinic. Emergency department visits by new or previous visit status, referral, complaint status (routine, urgent, or emergency), and disposition (discharged home, admitted to inpatient service, or requiring followup in the emergency or outpatient clinic) are collected for each shift in the department.

Identifying, diagnostic, and treatment information contained in the medical record varies in detail and extent, depending upon the form used by the various specialty services. Basic data on patients is collected by means of a standard advance registration form used in the outpatient department, an outpatient admission record, clinic and medication sheets, and nurses' notes. Outpatient department service information, statistics on clinic visits, and figures on individual clinic attendance are obtained daily from a computer print-out check-in list of scheduled appointments. Monthly service statistics are gathered from the outpatient clinic attendance report. Service statistics collected for each of the three shifts in the emergency clinics are recorded in the emergency department day sheet (listing each patient by name and other identification with data pertaining to arrival, referral, complaint

status, treatment, doctor, and disposition) and in the daily clinic report, which highlights the number of patient visits by service.

Medical Records

Information contained in patient medical records is entered on appropriate forms by the hospital staff responsible for particular entries. Data pertaining to diagnosis, treatment, tests, and other procedures are recorded by various professionals (physician, surgeon, pathologist, anesthesiologist, nurse, laboratory technician) having contact with patients. Identifying and admission information is entered on the admission record by the admission officer, who also codes the geographic area of residence and financial information.[1] In the outpatient department, information obtained from advance registration forms completed by the parents of patients is transferred to the admission record.

Every new patient is assigned a permanent unit identification number at the time a medical record is created in the admission area. The patient's name is simply written on a pre-numbered medical record folder and on a control sheet numerically listing all patients treated at the hospital. The medical record folder, control sheet, and a master card are sent to the medical records

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[1]Geographical and financial rating codes are recorded on the admission record in accordance with codes designated in the Center's coding conventions manual.

department where they are checked for accuracy and completeness. Then a copy of the admission sheet is sent to the outpatient admission area, after which it is forwarded to the tabulating department for keypunching. IBM cards containing patient unit number and identifying and financial information are fed into the computer system to update the patient index file. After medical record numbers have been assigned, any changes in them must be made off-line by the medical record staff.

The medical record department is the storage and retrieval area for all medical records. Medical record folders are filed sequentially by reference to the patient's identification number, according to active or inactive stage of use. Inactive records are kept for seven years within an area designated for storage of most recent or frequently used records; thereafter, they are transferred to permanent inactive storage files and kept for 55 years.[2] Some records which had been inactive over 20 years have been microfilmed, but this practice has been discontinued because microfilming did not alleviate storage problems. Furthermore, it is anticipated that medical record data will be stored in machine-readable form in one medium or another. At any rate, records at any stage of filing can be recalled when the patient returns for care.

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[2]Some inactive records over 20 years old are stored off the hospital premises in the New England General Hospital Archival Storages.

Within the computerized outpatient department, medical record requests are anticipated by reference to the computer listing of scheduled clinic appointments and forwarded to the medical record area two days prior to the date of visit. The records are transmitted by conveyor belt to the service area.

Access to medical records is limited to staff physicians responsible for supplying missing information and to professional and student staff involved in medical research. Abstracted medical record information is released to outside agencies and individuals only after decision has been reached that the use of the information is legitimate; that is, legally sanctioned and in the best interest of the patient. Direct patient authorization is required for release of information to lawyers and to certain social agencies. Sensitive psychological and communicable disease data are released solely to persons directly involved. Communicable disease data, for example, are shared only with public health officials.

Service Statistics

When the computerized outpatient and emergency clinic information system is fully operational, clinic attendance statistics will be generated on-line. At present, clinic attendance data contained in the computer-stored patient record is coded and batch processed for entry into the system; outpatient and emergency clinic visit statistics are processed manually.

Attendance statistics for each of the outpatient clinics are

obtained from the computer print-out listing of scheduled appointments. The print-out, made available to the scheduled clinic the day prior to the appointment, serves as a check-in sheet for recording attendance. The clinic secretary who receives the patient notes whether the appointment was kept, was cancelled, or whether the patient did not show. She enters the appropriate codes for attendance and visit status (e.g., new or former patient; that is, one who has made previous visits to the same clinic on or after October 1st of the current fiscal year). In addition, the source of referral (outside source, scheduled clinic, emergency department, or inpatient division) is coded for patients new to a specific clinic within Children's Hospital Medical Center. Coded print-out sheets are sent daily to the tabulating department for keypunching and batch entry into the computer-stored patient record. Daily results of attendance (total appointments kept, cancelled, or not kept) are reported to the outpatient department administrator. Monthly outpatient service statistics for the whole hospital consist of total daily clinic visits by category for the period. They are reported to the hospital administrator.

Emergency clinic statistics are gathered daily for each shift of the three clinics comprising the emergency department. The clinic secretary who receives patients records the fact of arrival, name, age, temperature, chief complaint, visit and referral status, and medical record number (if a former patient) on the emergency department day sheet. The daily clinic report,

giving an account of the number of patients treated for particular ailments, is completed by the head nurse. Both collection forms are forwarded daily to the emergency department administrative office where they are filed and tabulated for monthly reports. The department administrator and physicians interested in the information contained therein from time to time refer to the descriptively detailed day sheet.

Service statistics are presented monthly in separate reports of the emergency department and the outpatient clinics and distributed internally to administrators and chiefs of service. Outside agencies such as United Community Services also receive copies. These statistics are used in administration and planning as indicators of trends, for staff and departmental needs, and in similar ways. They fulfill accreditation and other reporting requirements. Yearly summaries are published in the Children's Hospital Medical Center annual report.

Problems

Two problems affecting the on-line system are slow response time and inadquate storage capacity. The current transmittal rate of 300 characters per second requires that three transmissions be made for each appointment. Response time will be increased to 42,000 characters per second when a second computer is installed. There is no easy solution for limitations in storage capacity. The present system restricts the patient index file to 200 characters

per record. It is an obstacle to adding items of information to the on-line patient record. Yet records of larger length stored in disk memory present difficulties in retrieval.

Additional Information Needed and Plans for Improvement

The staff of the Children's Hospital Medical Center feels that effective administration and planning require evaluative data on patient care. Additional information on utilization patterns (e.g., the number of clinic visits by diagnosis, the number of clinic visits by discharge status, and inter-hospital mobility patterns for outpatient services) has high priority, but sociological data on patient, family, and the surrounding community are also desirable.[3]

Computer capabilities will be extended to encompass collection of additional information needed for planning optimum patient care. This will include information on the length of time necessary for treatment of various conditions, treatment continuity, and patterns of staff allocation. Integration of the emergency department with the on-line outpatient system will eliminate the present system of internal referral. It will permit direct followup of emergency patients by means of on-line outpatient and inpatient appointment scheduling. Requests for medical records of patients scheduled for appointment can be made on a real-time basis when a

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[3]Plans are to collect limited sociological data on the population in the Heath-Bromley area, served by the Martha Eliot satellite clinic of Children's Hospital Medical Center.

teletype area is built into the medical record library. The system will also encompass on-line referral and appointment statistics when an additional computer is installed. Installation of terminals in the X-ray and laboratory areas in January 1969 will bring automation to the ancillary services.

Additional medical information will be appended to the patient computer record, at present containing only basic identifying and appointment status data. Diagnosis, blood type, immunization and communicable disease information, and a patient assignment code (derived from the scheduling of patients to specific doctors) will be programmed into the system. Patient assignment coding should exert considerable influence over the continuity of care. Comparable information will eventually be gathered on patients in the private ambulatory service, currently excluded from the central computer system. Although private physicians have not reached consensus on the need for such information, there has been movement toward integration through the collection of X-ray data on private outpatients.

Ability and Willingness to Participate in a Community-Wide Information System

Executives at Children's Hospital Medical Center have amassed considerable experience in applying computer technology to hospital affairs. They had rather definite and pragmatic views about the feasibility of developing a community-wide health and welfare information system in the near future. They felt that three

systems, rather than one, appeared warranted in face of divergent auspices and interests among agencies. State agencies, they thought, might be included in one system, private social and public welfare agencies in another, and hospitals and extended care facilities in a third. They recognized that the second system, comprising private social and public welfare agencies, while logical because of similar function, might be a problem because of mixed auspices.

Among alternative types of information systems which could be developed, a community facilities and resource inventory, susceptible to continuous and timely updating, was considered the least threatening. It was felt that the problem of confidentiality would not be solved for some time. Any system, therefore, would have to skirt this issue. Development of a computerized directory of information stored in various agencies, while not controversial, was not considered sufficiently useful to justify investment of the resources necessary to accomplish the task. Children's Hospital Medical Center executives thought that creation of an archive containing abstracts of health, welfare, and social agency records, or even a central registry of patients and clients served by organizations in the metropolitan area, was premature. They cited hardware and program incompatibilities and lack of consensus about which variables to use in describing service populations as principal obstacles to information sharing between hospitals at present. In their opinion, diagnosis and laboratory test results were

most suitable for computer processing and transmission. Other types of information would have to await breakthroughs in natural language programming and processing.

A conservative yet well-considered position was taken on the issue of confidentiality. Identification of individuals appeared at issue when an archive or a patient index was mentioned. They would insist, therefore, that patient consent be made a necessary precondition to acknowledgement by an institution that the patient was known to it. As long as hospitals had to hold the "legal bag," they would have to play it conservatively. Any exceptions involving information sharing without patient consent, including discussions between physicians without justifying excuse, are not made public. And though computers may provide greater security than manual record-keeping and processing systems, that argument is not likely to convince hospital legal counsel. It was felt that legal counsel would reply that diminution of the probability that the system could be breached does not reduce legal culpability. This principle also was extended to cover identification of exact patient addresses as a basis for geographic record linkage. Geographic coding more precise than the neighborhood block seemed untenable. If more precise coding were to be used, data processing would have to take place within the institution under strict controls. Maximum identification permissible when sharing abstracts with an information system such as the Blue Cross Data Service is the patient identification number assigned by the hospital.

Executives at Children's Hospital Medical Center took a pragmatic position on what auspices seemed most appropriate for developing an information system. They considered government auspices necessary if large sums of money were to be obtained to develop any kind of a community-wide information system--despite the greater trust which private, voluntary organizations might engender. However, private auspices were considered too unstable to persevere to completion of such a large-scale project. When the drama had gone, they felt, private organizations might tire. Slow, prodding government, on the other hand, seemed more likely to follow through to completion.

Finally, four reasons were offered why a data bank storing information on individuals was premature. First, "Big Brother" is psychologically real. Meditag and Medicard systems have been slow to win acceptance. People prefer not to be identified by number or insignia as special risk persons, although such identification might benefit them at some time. Second, there are too many legal problems involving individual confidentiality. In fact, the payment and record system in medicine is always a potential threat to the individual. Until people are guaranteed protection against use of medical information to injure their security with respect to employment, social position, and economic status, physicians would remain reluctant to share information. Third, the data obtained are untrustworthy. Professionals distrust other professionals in matters of diagnosis, for example.

Fourth, some managers fear over-quantification of decision making. The trend to place undue emphasis upon quantifiable variables, ignoring other just as valid qualitative data, is causing some negative reaction among younger executives. They themselves fear getting "lost in the system."

In sum, an information system which confined itself to institutional data and steered away from information pinpointing individuals and professionals was considered most feasible. Up-to-date information on admission policies, availability of various categories of beds, occupancy status or caseload, and range of services offered would be most useful to hospitals scanning the community for additonal resources for patients.

CHAPTER IX

COMPUTERIZED MANAGEMENT INFORMATION SYSTEM OF ASSOCIATED CATHOLIC HOSPITALS, INC.

Introduction

Associated Catholic Hospitals, Inc., was established to eliminate overlap and duplication of basic services among Catholic hospitals of the Boston Archdiocese. Thus far, its operations provide ADP services and central laundry services to St. Elizabeth's Hospital in Brighton, St. Margaret's Hospital in Dorchester, and Cardinal Cushing Hospital in Brockton. The three hospitals have joined together on a demonstration basis with the expectation that other Catholic hospitals will join when the benefits of membership become apparent.

In two years an on-line, real-time sharing system based on the IBM 360-40 computer has been developed for handling data concerning accounts receivable/patient billing, census, admissions, patient transfers, laboratory procedures, central supplies and nursing requisitions, and other hospital routines. When accounts payable, the general ledger, and various costing centers are brought into the system, a hospital management information system will link member hospitals into a coordinated whole.

The ADP service division of Associated Catholic Hospitals employs 10 persons and provides 7-day, 24-hour coverage of the three hospitals. Below the executive director, there are one systems engineer, four programmers, three operators, and one secretary. The three hospitals together employ the full-time equivalent of 10 or 11 keypunchers. Development costs to date are not available for publication; neither are annual ADP service budgets. A coordinating committee, consisting of the Associated Catholic Hospital executive director and systems engineer and the comptrollers of the three hospitals, have worked to develop and implement the system.

Associated Catholic Hospitals, Inc., has progressed further than any other hospital group in Metropolitan Boston in establishing a hospital management system. It has begun the process of linking an important group of sectarian health agencies into an integrated whole. The challenges it has met and overcome, as well as the problems which remain, provide valuable lessons in systems design and development within a hospital environment.

On-Line Hospital Management System

The three member hospitals--St. Margaret's, St. Elizabeth's, and Cardinal Cushing--comprise the core of what ultimately will become a complex of hospitals, schools, and ecclesiastical facilities subscribing to the Associated Catholic Hospitals system. Implementation will proceed in three phases. The first, a complete financial

system, is under development. The second and third phases will yield, respectively, a medical information system, including automated nursing stations, and a system permitting flexible access to files for clinical research.

Input-output communication terminals at each hospital are connected on-line by means of standard telephone lines with the IBM System 360-40 computer in Brighton. The hospitals have direct access to patient files stored in the computer. Patient data are transmitted back and forth between the hospitals and the computer throughout the day. Random access permits fast retrieval of any patient's record for posting, billing, or inquiry. When the hospitals have completed all on-line transactions at the end of the day, the terminals are turned off. The computer then returns to an internal mode while processing patient data for scheduled financial and statistical reports.

The IBM System 360-40 Computer

The IBM System 360-40 computer has a central processing unit with a memory capacity of 65,536 characters and the circuitry necessary to control the input, output, arithmetic, and logical functions of the system. Attached to the central processor are three control units. One unit controls transmissions over the terminals; a second contains control and buffer storage for the card reader and printer; and a third permits functional attachment of disk storage drives to the computer. The latter interprets and

executes all orders from the system and checks the validity of data transferred to and from random access devices.

A console attached to the central processing unit provides communication between the operator and the system. A high-speed printer generates print-outs and reports at 600 lines per minute. A card reader-puncher with capabilities of 402 cards per minute read-in and 270 cards per minute punch-out gives the system high-speed card input and output. Three disk storage drives with removable disk pack files, which can store up to 7.25 million characters each, give the system extremely fast on-line direct access storage.

The on-line communications system to the computer consists of three on-line terminals, one for each hospital location. The terminals have the following components: (1) a control unit to provide control logic over the system; (2) a printer-keyboard to produce hard copy and to permit manual entry of data into the system when making inquiries; and (3) a card reader to transmit data pre-recorded on punched cards.

Inpatient Data Flow

Throughout the day, each hospital transmits patient data on-line to the computer patient files at the Data Processing Center. Patient records stored in the computer include patient master record, insurance, summary charges, detail charges, charges description, price and revenue summary records, accounts receivable, master

and insurance records, and census file. Approximately 43 standarized forms, reports, and programs cover every aspect of patient processing. Basic patient data contained in the master record are obtained from the admission form. Various laboratory test forms and patient charge tickets, generated in nursing units or service departments, and cash deposits made by mail or with the cashier are recorded in patient accounts by means of real-time record updating. Data obtained during various stages of patient care are sent to the business office for processing. Patient charge tickets, cash receipts, admission documents, and insurance forms obtained at the time of admission are keypunched, verified, and transmitted via the terminal card reader. Hospitals can retrieve patient data from the computer at any time during the day. Data include billing information inquiries, insurance verification, and special coverage information needed for insurance control.

After the last daily on-line transmission from each hospital, the terminals are turned off and the computer returns to an internal mode of operation for further processing of patient data. Data updating output produces various daily reports transmitted to the respective hospitals as the first on-line activity each morning. Hard copy reports generated by the terminal printer include hospital census reports of daily transfers, discharges, and admissions, a cash receipts report, an income report by service, and inpatient discharge bills. Periodically, the system also produces financial statistics, an insurance billing total by service report, and monthly income reports. Each day, the Data

Processing Center prepares various weekly and final patient statements and insurance bills. These computer-produced statements are sent directly to the parties responsible for payment.

Data Collection

A multi-part admission form is used to obtain and disseminate throughout the hospital basic identifying, financial, and admission information on patients. Identifying data include name, address, age, sex, race, marital status, birth date and birthplace, religion and parish, social security number, occupation, employer, and employer's address. Admission data comprise year of last admission; type of admission; name of attending and referring doctor; number of room and bed assigned; type of service; type of accommodation requested, received, and reserved; admission diagnosis; and name and relationship of person to be notified in an emergency. For obstetrical patients, the husband's full name, age, race, address, and occupation are obtained. Information gathered for the financial record includes name, address, occupation, employer and employer's address, number of years of present employment of the guarantor, financial class assigned, amount of advance deposit paid, and detailed hospital insurance coverage and other third-party payer information.

The above information, together with the assigned hospital number and admission diagnosis, is transmitted to the computer patient file. Other copies of the form, varying in detail, are

distributed and filed in several areas, including the medical record room, nursing floor, credit office, laboratory, X-ray, anesthesia, blood bank, social service, and information desk. Later, when the patient is discharged, the following information is recorded on it: final diagnosis, secondary diagnosis, operations and treatment, complications and infections, consultations, and the patient's condition. Another copy of the form is used as a patient summary sheet on the nursing floor. The credit manager's copy, used for financial screening, details financial data relating to income and other assets.

Non-emergency inpatient admissions are facilitated by a pre-admission form. Designed as a self-containing pre-stamped envelope, the form is issued to patients requiring hospitalization by staff physicians making reservations. When completed forms are received in the admission office, they are checked for completeness. Missing information is obtained by telephoning the patient. Identifying, admission, and financial data are transferred from the pre-admission to the admission form, which is filed and updated when the patient is admitted.

Problems

Automation implies redesign of the existing system. It requires reorganization and retraining of each and every person in the system. Public relations assumes paramount importance. Associated Catholic Hospitals anticipated difficulty in writing programs to make the System 360-40 perform to its specifications.

Instead, the human learning curve presented the greatest obstacle and challenge. Running the billing system parallel for 60 days placed added strain on the staff. Both manual and automated versions had inherent sources of error. Consequently, future conversions will be made abruptly, and imperfections in the new system cleared up afterward.

Another hurdle to overcome was procurement of technical staff able to design and develop a system without unduly disrupting patient care. Trial and error has helped the staff acquire the necessary attitudes and skills. Fortunately, the comptrollers of the three hospitals understood the issues and were high enough in the organizational hierarchy to make basic decisions affecting standardization of hospital forms, procedures in the business office, and computer inputs. Finally, computer vendors are always remiss in providing software packages which work on the equipment installed without modification. Technical staff had to ferret out and debug vendor program errors.

Additonal Information Needed and Plans for Improvement

Associated Catholic Hospitals envisions developing a total and general hospital management system which will permit control of all functions of the hospital. Such a system will identify where costs are accruing, pinpointing profit and loss areas. Although progress to date has been on the financial and business end of the operation, nursing and individual care will follow. Automated laboratories will speed diagnosis and treatment.

Associated Catholic Hospitals plans to bring other hospitals, both sectarian and nonsectarian, into the system as a means of reducing per unit costs. Unlike Massachusetts Hospital Association, however, it does not intend to engage in marketing activities. It expects other hospitals to seek entry when the system clearly demonstrates its capabilities.

Ability and Willingness to Participate in a Community-Wide Information System

Policy decisions affecting release and use of information processed by Associated Catholic Hospitals are the prerogative of the participating hospitals. Executives of Associated Catholic Hospitals refer all policy questions to the executives and boards of their membership. It was necessary, therefore, to survey St. Elizabeth's Hospital and St. Margaret's Hospital separately to ascertain what position they might take regarding development of a community-wide health and welfare information system.[1]

St. Elizabeth's Hospital

St. Elizabeth's has participated in a Blue Cross-Blue Shield data system since May 1, 1968. There has been some difficulty in obtaining timely discharge diagnoses. Coding surgical cases upon which several types of procedures were performed over a period of time also poses some problems. By June 15 the hospital had caught up on discharges through May 20, 1968.

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[1]Cardinal Cushing Hospital in Brockton, Massachusetts, was not surveyed because it lay outside the geographic scope of the study--the Boston SMSA.

It requires two experienced medical library clerks, each paid $90 per week, to abstract, on the average, the records of 35 patients discharged daily, or 245 records per week. In the future, St. Elizabeth's Hospital may use its own computer at Associated Catholic Hospitals to generate abstracts for transmission to the Blue-Cross-Blue Shield Utilization Review and Provider Service System.

St. Elizabeth's Hospital would not participate in any kind of system which identifies patients by name. The Blue Cross -Blue shield system was acceptable because it used hospital identification numbers to distinguish patients. Exact address coding as a means of linking records to small geographic areas would be acceptable if there were special provision for safeguarding the identity of persons living in single dwelling units. There was no interest in an information system which simply revealed what information was stored in various agencies. Present reporting systems of the Division of Hospital Facilities of the Massachusetts Department of Public Health and of the Greater Boston Hospital Council were considered adequate for obtaining information on bed utilization and costs. Data on St. Elizabeth's Hospital personnel, their job descriptions, and salaries could be obtained, although there is some suspicion when other hospitals seek such information.[2]

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[2] It was felt that hospitals play it "close to the chest" on the matter of nursing personnel practices and salaries. Hospitals, in seeking to remain competitive on salaries, try to ascertain what other hospitals are paying. Allegedly, information reported by one hospital to another in this regard is often false.

Except for identifiable abstracts of patient records, St. Elizabeth's Hospital could contribute just about every other item of information to a community-wide system. Aggregated summaries were the least problematic with one exception--profit and loss status. Before third-party payments, hospitals could make money and distribute it outside of the organization. In the past, this had occurred at St. Elizabeth's Hospital. As a consequence, St. Elizabeth's Hospital has never published an annual report. It simply files the mandatory financial statement in the secretary of state's office.

There was some ambivalence about which auspices might prove best for developing a health and welfare information system. Although the state has certain rights and an ever-increasing measure of control over hospitals, it was felt that Blue Cross has the confidence of the hospitals and the medical profession regarding the special interests of hospitals and physicians and the issue of confidentiality. If, therefore, Blue Cross could master the resources and popular support, it might prove as good a location for a health information system as the state.

St. Margaret's Hospital

Executive opinion at St. Margaret's Hospital was more conservative than at St. Elizabeth's Hospital. None of the alternative forms of community-wide health and welfare information systems appeared useful. Development of a computerized directory

listing information available to authorized persons within health and welfare agencies, while innocuous, did not seem worthy of the effort. Both a patient index and an archive containing abstracts of records were considered potential threats to the 150 or more unwed mothers who give birth at St. Margaret's Hospital each year. Similarly, patients treated for venereal disease might suffer. St. Margaret's Hospital requires prior written authorization of patients before releasing information.

On the other hand, summary statistics could be freely contributed to an information system. Rates, fiscal and program data, and salaries are considered matters of public record. However, the decision to release a complete fiscal accounting of the hospital would have to come from the board of trustees.

Although St. Margaret's Hospital was dubious about the usefulness of any community-wide information system, including one which depended upon geographic-based record linkage, it might agree to participate under certain conditions. The majority of hospitals in Metropolitan Boston would have to reach consensus and decide to move ahead; costs of participation would have to be reasonable; and the product would have to be worthwhile. The Greater Boston Hospital Council, the Massachusetts Hospital Association, or other established voluntary, nonprofit organizations were preferable auspices for undertaking development of a system linking hospitals. Governmental auspices was considered likely to bog down a system in red tape.

In summary, executive opinion was critical of the very notion of establishing a community-wide health and welfare information system. Stringent preconditions to participation, in effect, promise nothing. The current interest of government in establishing, in lieu of a national data center, metropolitan or regional information systems was viewed as symptomatic of the gradual erosion of personal liberties taking place in the United States.

CHAPTER X

MORBIDITY DATA COLLECTION SYSTEM OF THE BOSTON DEPARTMENT OF HEALTH AND HOSPITALS

Introduction

The amalgamation of several municipal health organizations into the Boston Department of Health and Hospitals may result in an unprecedented coordination of health services and resources for Boston residents. At present, however, the situation is transitional and is fraught with organizational stress and strain.

In 1966, Boston City Hospital spent $23,605,783 in the care of 27,462 inpatients and in providing outpatient services to patients making 306,272 visits. Its Long Island Hospital Division spent $2,825,424 on 1,238 inpatients. Boston City Hospital had 3,600 full- and part-time personnel (the full-time equivalent of 3,300 persons). Long Island Hospital had 376 full-time employees.

The Long Island Hospital Division is tied to Boston City Hospital in record keeping and processing. In 1966, they jointly employed the equivalent of 123 full-time persons and spent $765,500 in three departments devoted to record keeping and processing--medical records, data processing, and accounting. The data processing unit

employed 29 persons and cost $250,000 to maintain. It had its own keypunch and counter-sorter machines and extramural use of the Boston School Committee's IBM 1401 computer and various peripheral devices.

The Department of Health and Hospitals is now developing its own intramural computer facility. It is in the throes of reorganizing its record-keeping and processing function just to keep up with the demand. It is so far behind on untranscribed medical records that one official estimated it would cost about one-half million dollars to catch up. The Department of Health and Hospitals provides the larger portion of services to the economically deprived in the city of Boston. Since this segment of the population is extremely important from an epidemiological standpoint, the system for collecting significant morbidity data within the city of Boston has been selected for closer study.

Morbidity Data Collection System of The Medical Services Unit

The Medical Services Unit and the Tuberculosis Control Unit in the Bureau of Disease Control of the Department of Health and Hospitals are responsible for the collection of communicable disease information reported on residents and nonresidents in Boston. Statutes require that diseases declared dangerous to the public health be reported for control, detection, followup, and

epidemiological study by these units.[1]

Since the Medical Services Unit has responsibility for collecting morbidity data on a broader spectrum of disease than the Tuberculosis Control Unit, it is the focus of discussion in this report. The Medical Services Unit gathers as part of its communicable disease and rabies control programs the following information on reportable cases:

1. For all cases--name, address, age, sex, race, disease, date of onset, and name and address of the reporting physician.
2. For communicable disease cases
   a) For all diseases--parent's occupation, number of children in the family, school (grade and date of last attendance) or place of employment, hospitalization/location, isolation status at home, and whether other cases of the same disease exist in the home.
   b) For serious and highly contagious diseases--additionally, diagnosis (and test results), name and address of physician, hospital and date admitted, and transmission information relating to probable

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[1]This encompasses diseases which, under the authority of the General Laws, Chap. III, sec. 6 (revised in August 1964), are reportable to the local board of health. Venereal diseases are excluded as they are reportable directly to the State Department of Public Health. Information on the number of Boston resident venereal

source of infection, isolation, and contact quarantine.

3. For cases of animal bites--bodily location of the bite, treatment source and diagnosis, type of animal, dates on which animal was quarantined and released, and name and address of the owner.

Any source defined by statute as responsible for notification must report communicable disease and animal bite cases upon detection. Among those designated as responsible are physicians, hospitals, nurses, schools, and police departments. For the most part, cases are reported by physicians and hospitals.

Reports are made on official card forms which record identifying information, disease, date of onset, and any other information needed for followup. Diagnosis, test results, and other information obtained for followup of serious and highly contagious communicable diseases are recorded on the following special forms: central nervous system case record, hepatitis questionnaire, acute enteric diseases record, Rocky Mountain spotted fever report, and USPHS surveillance forms. A rabies control form is used to obtain information on the disposition of quarantined animals.[2]

The official card form is generally completed by a physician. Information on the communicable disease followup forms is recorded

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disease cases is reported monthly to the Unit and included in the annual report.

[2]Police send a separate and more detailed report than that required by the rabies report form when they become involved in restraining a dog.

Rabies control involves transmittal of the rabies control form necessary for dog quarantine to the Animal Rescue League or, when the dog belongs to a nonresident, to the State Division of Animal Health. Daily lists of cases involving dogs belonging to nonresidents are sent to the Bureau of Communicable Diseases, State Department of Public Health.

Communicable disease information is filed alphabetically by disease and street according to the activity status of the case. Rabies control information on dog and miscellaneous animal bites is filed alphabetically by the name of the person bitten and by the name of the resident or nonresident owner. Active and inactive files are maintained. The initial rabies report form and rabies control form are kept on file for five years. Communicable disease followup forms may be saved for 10 years, depending upon requirements for following up particular diseases. Most records are filed in the immediate work area of the Medical Services Unit, but voluminous files of earlier records are stored in an adjoining room.

The information contained in the files is used by the staff in case followup. Copies of communicable disease followup forms giving individual histories are sent to the State Division of Communicable Diseases. Access to individual records is restricted to authorized agencies and to individuals who can establish that they have legitimate need for the records in their research. Records are made available to lawyers only through court order. The records do contain information which could prove damaging

to persons or institutions. Loss of confidentiality might impair the reporting system.

The number of communicable disease and animal bite cases reported each year are tallied and published in the annual report of the Department of Health and Hospitals.

Problems

Reporting sources complicate followup by supplying illegible, incomplete, or inaccurate identifying information. Less serious cases of communicable disease are often not reported. It was estimated that only 40 percent of measles cases are reported. Gaps in reporting were not considered important as long as prevention of the disease could be effectuated through immunization.

Additional Information Needed and Plans for Improvement

Professional staff considered the data currently gathered adequate for present purposes. Vital information on serious disease is available through followup. Lack of information on innocuous diseases is mitigated by the fact that most of these diseases are just about eradicated or preventable by immunization. The National Communicable Disease Center's weekly report on "Morbidity and Mortality" ultimately depends upon the Medical Services Unit and similar units throughout the country for its morbidity data.

The Medical Services Unit has no concrete plans for changing the character of the present operation. It provides limited

quantitative information on the incidence of disease and animal bites. As the Department of Health and Hospitals develops its own computer facility, however, it may stimulate interest in its use among units of the department thus far not pressed by volume or complexity to automate.

Ability and Willingness to Participate in a Community-Wide Information System

Executive preference within the Department of Health and Hospitals tended to a central registry or exchange identifying patients and clients on whom additional information could be obtained by contacting the organizations serving them. An archive containing abstracts of patient records was considered the best of possible information systems but not feasible at this time. If the central registry were to become a reality, some uniform method of identifying individuals (e.g., social security number) would have to be employed. Similarly, it would be necessary to devise a system of "locks" controlling access to certain portions of the file and to make provision for logging users and their purposes. Persons known to the police and to certain health agencies would have to receive special protection from disclosure.

Ultimately, data derived from all sources in the community would support a "team" approach to diagnosis and treatment. As determined by circumstances, the team might consist of medical, welfare, and even police personnel. The composite data base might assist planners in establishing priorities. It was felt that the

mandate for organizations to get together to establish an integrated information system would have to come from the legislature. It would require integration of health and welfare functions under a single authority, perhaps a deputy mayor operationally responsible for health and welfare within the city of Boston. Then joint budgets could be devised to reflect composite experience with individuals and families requiring services from divisions of the integrated health and welfare organization. Teams of professionals could develop coordinated plans, and the sum of these plans would determine program- and product-oriented budgets. Past experience, coded and stored in a health and welfare information system, would facilitate projections and plans for the future.

With suitable safeguards, it was felt that the Department of Health and Hospitals could release to a community-wide information system abstracts of patients, individual data on personnel, program and operational data, and summary statistics. Safeguards might include formal agreements between organizations that their respective files could be accessed by one another. As a matter of fact, the Department of Health and Hospitals now transmits records to the Department of Public Welfare.

At the same time, there was recognition that a thorough review of the policies governing release of information on patients was needed. Such a review might clarify what is possible and not possible in this regard. Information on personnel, although related to individuals, would have to be limited to what are now

matters of public record. Such data would include whether a person is now employed, his job classification, job description, and salary. Data on efficiency and reprimands could not be released to an information system.

Official auspices for a community-wide information system was considered preferable. However, this did not imply a line organization. Rather, a public corporation, styled after the securities and Exchange Commission or Federal Reserve Board, appeared best suited to regulate and control the flow of information from and between organizations participating in the system. It was felt that the Department of Health and Hospitals had little autonomy at present and so stood to lose very little by joining other organizations in the development of an integrated information system. In so doing, it might perhaps share a place within a more unified departmental structure of municipal government.

CHAPTER XI

VITAL STATISTICS AND MORBIDITY DATA COLLECTION SYSTEMS OF THE MASSACHUSETTS DEPARTMENT OF PUBLIC HEALTH

Introduction

Within the Massachusetts Department of Public Health two basic, statewide information systems were selected for study. One, the Division of Health and Vital Statistics, is the repository of basic data on births, deaths, and marriages occurring in the Commonwealth. As one of the two systems of sufficient scope to provide information on the total population in Metropolitan Boston, it has great importance as one cornerstone of a community-wide health and welfare information system.

The other information system, in the Division of Communicable and Venereal Diseases, provides insight into a health intelligence and control system generating extremely sensitive data on persons actually infected with venereal disease, suspected of it, or in contact with infected individuals. The thought of incorporating venereal disease morbidity data into a community-wide information system raises a great number of ethical and legal questions--more so than do any other type of data. This information, if considered

important enough to include in a system, will challenge systems designers and developers to find ways to protect individual confidentiality and, at the same time, to convince public officials and their constituencies that the system does indeed provide protection.

The Division of Health and Vital Statistics employs nine full-time persons and 30 occasional part-time persons. Its most recent operating budget was $110,000. Of this amount, $75,000 was spent on statistical data processing. The Division uses the GE 415 computer at the Registry of Motor Vehicles without charge. It pays for the operators' time at overtime rates. The Division publishes an Annual Report of Vital Statistics, the latest of which covered the year ending December 31, 1965. The Division faces considerable problems in discharging its function because of budgetary limitations. It is just now compiling vital statistics for 1966.

The Division of Communicable and Venereal Diseases employs nine full-time persons for record keeping and processing--five for venereal disease, three for communicable disease, and one clerk for stenography and bookkeeping. Record-keeping and processing expenditures are slightly more than $66,000 per year. ADP equipment includes keypunch and verifier and an IBM 402 statistical accounting machine. Most recent total annual budget was $1,362,400, of which $450,800 was spent on venereal disease control and $911,600 on communicable disease programs. Of 37 employees in the Division, 21 were assigned to venereal disease control and 16 to communicable disease programs.

Division of Health and Vital Statistics: Processing of Birth, Death, and Marriage Records

The Division of Health and Vital Statistics derives and processes information from birth, marriage, death, and fetal death records of events occurring in Massachusetts to residents and non-residents and events occurring out-of-state to Massachusetts residents. More specifically, the following items of information are extracted from the respective records:

Birth Records--County, city or town, and hospital or other place of birth; sex; race; date of birth; mother's residence by county, city or town, and state; mother's age in years; whether person attending the birth was a physician, parent, nurse, or other person; birth weight; whether eyes were treated; multiple birth information, including number, birth order, and whether sibling was born alive or dead; number of children mother previously bore alive; and legitimacy status (whether the parents are married to each other).

Marriage Records--Place of marriage; month and year, county and city reporting; age of bride and groom as of the last birthday; number of marriages and previous marital status of bride and groom; and county and city or town of residence of bride and groom.

Death Records--Name; place of death by county and city or town; sex; race; marital status; age; residence by county, city or town, and state; date of death; primary cause of death; whether an autopsy was performed; and accidental death information, including place of death, type of injury, and occupation.

Fetal Death Records--Place of delivery by county, city or town, and hospital; date of delivery; sex; race; residence of mother by county, city or town, and state; mother's age in years; number of mother's previous deliveries; number of children presently living; number of children born alive and presently dead; total number born alive; previous fetal deaths; length of latest pregnancy; weight of fetus; time of death (whether before labor, during labor, no report, or unknown); whether an autopsy was performed; cause of death; whether person attending was a physician, parent, or other person; and multiple birth information, including number, birth order, and whether sibling was born alive or dead.

Original birth, death, and marriage records generally provide additional information, presently not extracted and processed. They contain, for example, the precise address where the event occurred. Birth records give full name, race, and occupation of parents and, where applicable, the secondary and tertiary causes of death of child. Death records give the occupation of the deceased, including status in the Armed Forces. Marriage certificates provide for both bride and groom name, race, occupation, birthplace, and name of father and maiden name of mother.

Data Collection

Source documents of vital events are made available to the Division of Health and Vital Statistics by the office of the secretary of state of the Commonwealth (state registrar) who, in turn, by statute

requires of town clerks copies of certificates of births, marriages, and deaths occurring within their jurisdictions. Reciprocal agreements between state registrars make possible transmission of copies of records of events occurring out-of-state to Massachusetts residents. Under statutory provision, physicians in attendance at birth, the parents, or the hospital or other institution in which birth takes place must register births with the town clerk. Similarly, officiating clergymen or magistrates are obliged to register marriages. Death certificates are registered by filing with the local board of health.

Completion and filing of vital records depends, in some instances, upon more than one responsible party. Birth records, completed by the physician in attendance at birth or by the hospital administrator, are verified by the mother or other responsible person. Officiating clergymen or magistrates are solely responsible for filing marriage certificates. Physicians use standard or fetal death certificates to report information on cause of death. Funeral directors add identifying information on the deceased to the death certificate when they file for a burial permit at the local board of health. When the medical examiner investigates cause of death, he files a special certificate of death.

The record forms used to obtain information on vital events include instructions for completion. When forms are revised or new forms are adopted, the state registrar holds informal training sessions for personnel in the town clerk's office who are affected.

The state registrar also sends written instructions to town clerks to clarify issues as they occur; for example, when persistent errors of consistency or completeness of information are discovered.

Copies of birth records are due in the office of the secretary of state within 60 days following the event from communities with a population of less than 50,000; they are due within 90 days from communities with a population greater than 50,000. Marriage and death certificates are reportable by the 10th of the month following the event. In practice, however, reporting does not adhere to schedule and is often late. Boston and other large cities often report births as much as six months late. The bulk of death records are received two to three months after occurrence because small towns tend to accumulate and send records in batches. Medical examiners' reports are held up for a year in complicated cases.

Birth, marriage, and death records received in the Division of Health and Vital Statistics are assigned individual identification numbers, corrected for obvious inaccuracies or incomplete data, coded, and keypunched. Then the records are returned to the office of the secretary of state.

IBM cards and yearly print-outs of all deaths in Massachusetts by name, age, sex, and cause of death can be distributed to "responsible individuals"--including universities, public and private agencies, and independent researchers--for use in planning and research. Under special arrangements, original copies of records are distributed to several agencies. These agencies include the

Peri-Natal Mortality Committee at the Boston Hospital for Women (copies of fetal and infant death records), the Division of Maternal and Child Health (records of maternal deaths), and Rescue of Boston, Inc. (reports of death by suicide). In addition, microfilms of all records are sent to the National Center for Vital Statistics in Washington, D.C.

Records Processing

Records received from the office of the secretary of state (state registrar) are machine-stamped with sequential identification number (the "state file number"), starting from the last assigned number of a particular file. They provide a sequential count of the number of records in the file processed during the year. Record file control cards are used to post the number of records received, the dates on which they were received and returned to the state registrar, the number received from each city or town, and the range of identification numbers assigned. Within approximately 60 days, records are processed and returned to the office of the secretary of state. An average of 18,000 records per month is processed.

Five statistical clerks, four working with the death records and one with birth records, are responsible for checking the accuracy of data and coding place of occurrence, residence, and

cause of death. Other items of information are coded as the record is keypunched.[1]

Inconsistent, ambiguous, or incomplete information is checked and clarified by contacting the persons responsible for recording the information. Birth and marriage records are clarified with the assistance of the town clerk, while checking information on cause of death requires direct contact with the physician who signed the death certificate. The information on the birth certificate noting whether or not the mother's verification was obtained is disregarded.[2]

It is not known how frequently query or followup for clarification is necessary. It probably occurs most often in coding cause of death on the death records because assignment of the code for primary cause of death requires unambiguous information. Place of occurrence (hospital or other institution for births and fetal deaths) and residence are coded according to county, city or town, and state codes. Exact street address is not coded. Codes

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[1]In addition to the in-service training which all personnel receive, coders of death records receive formal training in use of the International Code of Deaths at the Regional Center for Health Statistics.

[2]Mother's verification is not always obtained by town clerks. After sending a second notice to the mother requesting verification, if there is no reply, the record is simply accepted as it stands. Birth certificates make provision for noting whether verification was obtained. However, town clerks do not always complete the item. In any event, the information is processed as received without regard to this factor. How often it occurs and its influence on the accuracy of the data have not been determined.

for primary cause of deaths are derived from The Manual of the International Statistical Classification of Diseases, Injuries, and Causes of Death, Volumes 1 and 2, or a more recent supplement, The Vital Statistics Instruction Manual--Cause of Death Coding for Deaths, published by the U.S. Department of Health, Education, and Welfare, Public Health Service, Division of National Center for Health Statistics. In addition, deaths caused by accidents are coded by type of accident, occupation of the deceased, and county, city or town, and state where injury took place.

Three keypunch operators follow card format designations in punching partially coded records. As they proceed through the record, they assign codes (largely by rote) to uncoded items and punch simultaneously. Accuracy of processing is controlled by 100 percent verification of keypunched cards and maintenance of a detailed workflow log, which facilitates tracing errors back to the microfilmed source records.

Verification of keypunched cards is particularly important as it relates to information coded directly during keypunching. Place of occurrence, residence, and cause of death codes are not validated because the computer program has a validity check built in to detect obvious or conditional errors. A study of cause of death reporting, comparing a 10 percent sample of death records coded in the Division of Health and Vital Statistics with the same records independently coded by the National Center for Health

Statistics from microfilmed records sent to Washington, disclosed only a 1 percent discrepancy.

Data Analysis

Punched cards are processed at the Registry of Motor Vehicles on the GE 415 computer. The Division does not have to pay for use of the computer between 10 p.m. and 2 a.m., Monday through Friday. However, it does have to pay the operator overtime rates for his time. Aggregate counts, frequency distributions, cross-tabulations, and measures of association on a percentile ratio are computed.

Results are published in the Annual Report of Vital Statistics, also referred to as Public Document Number One. The National Safety Council, the Crippled Children's Society, and others use the report for epidemiological research purposes.

At present, information in card form is kept on file within the Division only until statistics for the annual report have been generated. Afterward, the cards are thrown out--either destroyed or given to groups which might have some use for them. The 1965 death record cards, for example, were given to the Statistical Unit of the Division of Adult Health, State Department of Public Health, where they have been employed in studying the geographic distribution of various types of cancer. Microfilms of the source records are purchased from the office of the secretary of state and permanently stored in the Division. When the computer at the Registry of Motor Vehicles acquires tape drive capacity, information now on punched cards will be stored in tape form.

Problems

The Division of Health and Vital Statistics faces major problems due to understaffing, lack of basic equipment such as a counter-sorter, a reduced budget, and difficulties related to reporting, collecting, and processing of the data.[3] In processing approximately 180,000 birth, marriage, and death records annually, the Division often has a backlog of about 20,000 records. Dependence upon the office of the secretary of state as the source of data causes considerable delay. Fetal deaths are not adequately reported. In cases of multiple births, it is not possible to obtain an accurate account of the number of living births or the deaths after delivery because death reports at present precede reports of birth. Cause of death coding for 1968 records cannot be revised in time to conform with changes in the International Code of Diseases, Adapted. Revised codes will not be effective until 1969.

Additional Information Needed and Plans for Improvement

If the budget were increased, the Division would regard the following additional information as desirable: secondary and tertiary causes of death, occupation, socioeconomic characteristics,

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[3]Staff needs include a keypunch operator, an administrative assistant, a programmer, a systems analyst, and coders. As an example of budgetary deficiencies, it was pointed out that $48 was allotted for the annual rental of a Xerox machine. It costs $100 per month to pay for machine rental and the volume of work within the Division.

and information relating to the first three months of pregnancy (for use in nutrition studies). It would also like to report mortality findings on a monthly basis so that the Communicable Diseases Division of the Department of Public Health could make cross-tabulations of mortality with morbidity data.

Occupation and secondary and tertiary causes of death, necessary for effective research and epidemiological purposes, are reported on the certificates but are not processed. Occupation is coded for accidental deaths only. A new computer program makes provision for inclusion of secondary and tertiary causes of death, but it will not make a difference until 1969 because there is not enough time to go back and reprocess 1968 records already coded and punched in the old way.

The Division foresees development of a New England Vital Statistics Information Center with capacity for linking records and processing information derived from the six participating states. Adoption of standardized card formats and agreements on the use of eight or 10 major tables for reporting data are first steps in that direction.

Some basic changes in the system of reporting births have been made recently. They become effective January 1969. In part, the changes anticipated legislation against reporting race--an exclusion which would critically affect reporting on the regional and national levels. The new system calls for direct registration by hospitals and provides a separate confidential section in the

record for reporting sensitive information. It will eliminate many of the problems now obstructing the present system. Specifically, mother's verification will be obtained prior to her discharge from the hospital and birth records will become available prior to death records.

Under the provisions of the amended birth certificate bill, a "confidential section" will be sent by hospital administrators directly to the commissioner of public health for administrative, research, and statistical purposes. The bill specifically calls for inclusion of color in the confidential section but leaves open collection of any other information necessary for such purposes "as the commissioner of public health shall certify to the Secretary of the Commonwealth" and provides for nondisclosure of the confidential section as a public record.

The Division has drafted a "confidential section" form seeking certain items of medical and health information relating to birth. It requests identifying information on race and education of the parents and also information on previous deliveries (number of children now living, the number born alive, the number born dead, date of last birth, and date of last death). The form is to be completed by the mother prior to discharge from the hospital. The attending physician is to provide information relating to the history of the pregnancy (date of last normal menses, month of pregnancy in which pre-natal care began, number of pre-ntal visits, complications related to pregnancy, other complications, and complications of labor). He also is to provide information relating to birth (whether "legitimate," the birth weight, birth injuries to the child, congenital malformations or abnormalities of the child, and whether the child left the hospital alive).

Operation of the new system on an experimental basis during the month of June 1968 has been made possible by a Federal purchase order. Direct birth-reporting from three Boston hospitals--Chelsea Naval Hospital, Boston Hospital for Women, and St. Margaret's Hospital--is expected to yield 1,200 records for the month. Experience thus far indicates reluctance on the part of some private physicians to supply the medical history information requested in the confidential section. The Division must overcome this resistance if the data are to have any value in the aggregate.

Division of Communicable and Venereal Diseases: Venereal Disease Morbidity Data

The Division of Communicable and Venereal Diseases has been empowered by statute to discover and control all venereal disease cases occurring in the Commonwealth. It collects identifying information (name, address, age, sex, race, marital status, and occupation), differential diagnosis, and date and source of report on all diagnosed, contact, or suspected cases. In addition, for diagnosed cases, the previous history and the number of contacts are obtained; for suspected cases, the reason for suspicion; and for contact cases, the contact's relationship to the patient (if a prostitute, how procured) and the place and address of encounter and exposure.

Reports of diagnosed cases and their contacts are required by statute from all sources of detection, including private

physicians, hospitals, and mental and penal institutions.[4] Forms used for case reporting and contact followup include the standard morbidity report form, issued to private physicians and institutions not participating in the followup program, and special registration and followup forms used in 22 venereal disease clinics. The clinics obtain more detailed information than that provided by the standard morbidity form. For example, registration cards completed on all first-time visitors to clinics ascertain education, the reason for the visit (contact, suspect, or other), and information concerning encounter and exposure. Diagnostic cards and epidemiological report forms record diagnoses, contact and/or suspect identification, and disposition.

All items on the standard morbidity report form are to be completed by physicians detecting cases of venereal disease. There is a division of labor within venereal disease clinics. Clinic clerks transfer identifying and diagnostic information on to clinic registration and diagnosis cards from clinic records prepared by nurse interviewers and physicians. Nurse interviewers obtain identifying information from patients visiting the clinic for the first time. The physician, of course, makes the diagnosis and records it in the clinic record.

Information on contacts or suspects is obtained from infected patients by nurse interviewers and transcribed directly into the

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[4] Through reciprocal agreements, reports on Massachusetts residents are also obtained from other states.

epidemiological report. The epidemiological investigator assigned to contact or suspected cases has responsibility for entering information on disposition (including whether or not the person was located) into the epidemiological report.

To insure accurate and complete reporting, literature describing reporting procedures is distributed to physicians. Clinic personnel receive in-service training. They can also refer to a reporting manual containing sample forms and explicit directions for recording information. Prompt submission of reports to the Division of Communicable and Venereal Disease facilitates followup and control. Clinics send a copy of the epidemiological report, identifying contacts or suspects to be followed up, on the day a patient is first seen. Three clerks in the Division are responsible for daily processing of information necessary for followup, maintenance of an updated register, and statistics. Maintenance of an updated register of all cases requiring followup entails transference of contact information from standard morbidity reports submitted by physicians and others to epidemiological report forms, one for each contact.

Information relating to individual identification, diagnosis, date and source of report, and similar facts gathered on cases, contacts, and suspects is coded and keypunched. Before processing, forms are checked for obvious errors in consistency and for incomplete information. Coding manuals and card format designations guide coding and keypunching. Cards are 100 percent verified.

Completed forms and cards are filed in the Division for easy access and reference by staff. Morbidity reports, clinic registration forms, and diagnosis cards, filed by city and town of referring physician or institution and by clinic number and month of report, are kept for three or four years. Epidemiological reports are maintained in an active file until followup has been completed and disposition entered. Inactive epidemiological reports are filed by serial number and retained for at least 10 years. IBM cards are permanently filed.

All data on file identify individuals. Access, therefore, is limited to Division staff. Nevertheless, copies of epidemiolgical reports may also be found in the files of both the patient and the assigned epidemiologist in clinics participating in the venereal disease control program. Epidemiological reports on members of the Armed Forces are shared with Armed Forces authorities upon request. Despite the statutory guarantee of unconditional confidentiality, the Division receives many requests from attorneys for information on individuals. Without exception, these requests are refused.

Aggregate counts, frequency distributions, and cross-tabulations are published in the annual report of the State Department of Public Health. Statistical reporting to the National Communicable Disease Center in Washington, D.C., is reflected in the following reports of the Center: Quarterly Epidemiological Activity Report for Venereal Disease, Venereal Disease Morbidity Report, and Semi-

Annual Report of the Civilian Cases of Primary and Secondary Syphylis and Gonorrhea by Reporting Source, Color, Sex, and Age Group.

Notification of the number of cases reported on residents of the various cities and towns is made monthly to local boards of health. Military and civilian cases by place of encounter and exposure in various cities and towns are reported monthly to the Armed Forces. This information is also used for regulatory purposes by various licensing boards in taking action against high-incidence establishments. Finally, the director of the Division of Communicable and Venereal Diseases refers to aggregated data as he seeks to educate the public in lectures and talks.

Problems

Nonreporting of cases--particularly by private physicians--affects the accuracy of estimates of venereal disease incidence. It makes control through followup of contacts difficult.[5] Staff shortages limit

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[5] In 1965, the Division joined with 5 other state health departments in contracting with the National Opinion Research Center, University of Chicago, to study the problem of nonreporting. The physician attitude survey, reported in "Physicians' Attitudes Toward Venereal Disease Reporting," Journal of the American Medical Association, Vol. 202, No. 10 (December 1967), 117-22, indicated that selective reporting by physicians is the crux of the nonreporting problem. Cumulatively, it amounts to a large proportion of nonreporting. Reasons given for nonreporting lead to the belief that physicians do not fully trust the confidentiality of health department records or health department staffs. There was indication also that physicians do not completely understand how reports are the basis for tracing contacts. As a result of the study, the Massachusetts Medical Society passed a resolution making reporting of venereal disease cases an ethical issue. The problem, however, still exists.

full exploitation of the data collected for research, administrative, and planning purposes.

Additional Information Needed
and Plans for Improvement

Data currently collected are considered adequate for control purposes. An increase in budget would permit hiring of additional staff to subject existing data to additional analyses. A study of the sociological characteristics of clinic patients, for example, might prove useful. Information bearing on cyclical upsurges in the incidence of venereal disease in various areas, attributable to migration of patients (or prostitutes) from one city to another, should be analyzed weekly to assist location of the population most needing control. At present, information on population mobility is obtained from monthly reports of local law enforcement agencies, the Armed Forces, and the FBI.

It was felt that, for the present, the Division could get along without a computer-based information system. If, in the future, a computer-based system seemed desirable, it would be developed for exclusive use of Division staff and it would process information needed on a weekly basis.

Ability and Willingness to Participate
in a Community-Wide Information System

Five executives of the State Department of Public Health either were interviewed or responded by letter to the query about the Department's ability and willingness to participate in a community-

wide health and welfare information system. They had mixed opinions about developing a computer-based system to serve Metropolitan Boston.

Overall reactions ranged from "a computer-based health and welfare system serving the Metropolitan Boston area is extremely desirable" to stated fears about ADP as an end in itself and suspicions about "Big Brother." Executives of Lemuel Shattuck Hospital, administered by the Department, saw no difficulties in participating in a project for maintaining a data bank in Metropolitan Boston, provided that the hospital satisfied the legal requirements on confidentiality and had sufficient assistance to undertake the additional work.

One executive who preferred an archive containing machine-readable patient abstracts or a patient index as an intermediate step toward an archive, but who would not release identifiable abstracts without prior patient authorization, realized the inconsistency of his position. He did not consider a computerized directory of information stored in health and welfare agencies of much value to the Department.

Information on personnel, fiscal and program data, and statistical summaries can be obtained from the Department as matters of public record. If information of a personal nature were sought on personnel, authorization for its release would have to be obtained from the persons concerned. It was felt that the Department could make a major contribution in furnishing information on facilities

and programs both within and outside of the Department. These data are public record. One possible exception would be data which might be used for commercial purposes. The Department now scrutinizes requests for data in the aggregate from this standpoint.

The auspices under which to develop an information system was not considered an important issue. Public auspices, however, might lend more prestige than private, voluntary auspices.

The ability of the State Department of Public Health to participate in a computer-based information system is complicated by the state of its present record-keeping and processing apparatus. The Mitre Corporation surveyed the situation and informed the commissioner that it would take at least a year to convert to an integrated ADP system. The commissioner, commenting on deliberations in the Executive Office of the Governor about combining the Departments of Public Health, Mental Health, and Public Welfare to form a unified department, suggested that it might prove advantageous to design an information system which reflected the needs of the new, integrated organization. It was felt that systematic data on morbidity, mortality, days of restricted activity due to sickness, and similar facts by geographic area would meet the needs of the Department of Public Health for information with which to establish priorities among programs for various geographic areas. Above all, health information was not to be linked with commercial or police information systems.

CHAPTER XII

MEDICAL ASSISTANCE INFORMATION SYSTEM OF THE MASSACHUSETTS DEPARTMENT OF PUBLIC WELFARE

Introduction

The Massachusetts Department of Public Welfare recently acquired direct responsibility for administering general and categorical (e.g., Aid to Families with Dependent Children) assistance programs in 351 cities and towns of the Commonwealth. It continues its responsibility for maintenance of district offices rendering child welfare services through the Division of Child Guardianship.

Last year the Department served 359,562 persons. Total expenditures were $314,530,079, of which $281,000,000 was spend on public assistance, $4,530,000 to maintain the Division of Child Guardianship, $22,136,759 on administration of the public assistance program at the local level, $5,858,476 on central administration, and $984,838 on travel and staff education. The Department employs 4,077 employees, 748 in the central office and 3,329 in local offices.

The Department maintains a Bureau of Research and Statistics which processes summary statistics on various programs operated in

six district and 268 local offices. The Bureau of Research and Statistics shares with the Bureau of Accounts use of a variety of ADP equipment, including keypunches, a sorter-counter, a tabulator, a collator, an interpreter, and a reproducer. Between the Bureau of Research and Statistics and the Bureau of Accounts, the Department employed 145 persons and spent a total of $741,200 for record keeping and processing last year.

Medical Assistance Information System

The Massachusetts Department of Public Welfare maintains a data collection system primarily devoted to program services and expenditures. Case records on individuals are kept in local offices. Data on the characteristics of the populations served are collected on a sampling basis from local offices as required, either to meet Federal study commitments or for ad hoc studies. The absence of a master file on the population served and lack of direct access to case records demonstrates the decentralized nature of the information system and emphasis on routine collection of data for reimbursement and regulatory purposes.[1]

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[1]Fragmentary index files with name, social security number, and other identifying data do exist for some programs (e.g., Old Age Assistance) but not for the Medical Assistance Program. Identifying information (including name, birth date, sex, race, religion, legitimacy status, and family residence) is available in social data cards processed for applications, referrals, and placement of children in the Division of Child Guardianship. The social data cards do not include information on Medical Assistance status.

Medical assistance data are gathered on a monthly basis from local welfare departments and district offices of the Division of Child Guardianship. Data include information on service activity in the Medical Assistance Program (encompassing vendor medical payments to individuals eligible under the Old Age Assistance, Aid to Families with Dependent Children, and Disability Assistance Programs) and vendor payments under the General Relief Program.

Information is obtained on the number of Medical Assistance cases, the number of recipients (broken down by number of children and parents in families), expenditures in vendor medical payments by eligibility status, and medical expenditures for persons on other program grants.[2] Vendor medical bills, paid under the General Relief Program and the Medical Assistance Program (including amounts paid as deductibles and as coinsurance under Medicare), are reported by type of vendor,[3] the number of recipients, and the number of days of inpatient care purchased.

Monthly statistics kept on Medical Assistance cases include: (1) applications turnover in terms of the number of applications processed; (2) case turnover in terms of number of cases continued

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[2]Children under the supervision of the Division of Child Guardianship are eligible for the federally-sponsored Medical Assistance Program. They are reported under the classification "categorically unrelated families with needy children."

[3]Vendor types include acute and chronic inpatient hospitals, public medical institutions, licensed nursing homes, outpatient departments, laboratory and radiological services, physicians, dentists, other licensed medical practitioners, drug suppliers, and others not classified.

from the previous month; number of cases which are new, reopened, or transferred from one city or town to another; and number of cases closed, with reason for closing; and (3) total number of cases open by transfer status, vendor payment status, and active or inactive status. The number of persons (adults and children) represented in the totals of open and closed cases are categorized by correlative status in the OAA, AFDC, and DA programs or as unrelated to one of these programs.

Information gathered for reimbursement purposes details public assistance payment information, including vendor medical payments by program, and the names and social security numbers of persons in the account.[4] The total number of eligible recipients, total expenditures, and proportionate amount paid by Federal, state, and local governments for medical assistance are recorded for each city or town.

The Department is collecting special information for a Federal study of vendor medical payments on a 5 percent sample of all eligible persons receiving public welfare. Those eligible include individual recipients and, in the case of OAA and DA, persons essential for their care. They also include all members of families on AFDC. The information comprises name, age, sex, race, program status, number of drugs prescribed, and amount of monthly medical payments by

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[4]Use of social security numbers for identification purposes has been adopted as a uniform numbering system in the Commonwealth. Account numbers assigned in the local offices reflect local numbering systems and vary considerably. All welfare applicants are required to obtain a social security number if they do not have one. The use of the social security number as the "state case number" facilitated sample selection in one federally-sponsored study of public welfare recipients.

vendor type for the number of inpatient days of care or outpatient visits. Discharge diagnosis and number of days hospitalized are obtained for individuals receiving inpatient care in chronic and acute hospitals.

Three hundred fifty-one cities and towns report data monthly on Medical Assistance cases. Comparable information for children in the care of the Division of Child Guardianship is collected directly by reference to records of vendor medical payments within the Bureau of Accounts. The monthly statistical report and two supplementary forms are used to collect information on program services and expenditures. The monthly statistical report obtains general information on Medical Assistance cases (as well as on other programs of the Department). The supplementary forms concentrate on Medical Assistance cases and seek information on the number of cases, the number of recipients, and the amount of vendor payments by program eligibility and vendor type, as outlined above.

Information collected for reimbursement purposes, listing payments on accounts by name and social security number, is obtained by means of a roll of payments form. Special schedules are used to collect data on recipients sampled for inclusion in the Federal study of Medical Assistance.

The various forms are completed by clerks in the local welfare office responsible for maintaining program accounts--an operation centered on filing bills and recording payments onto individual

ledger cards. There are regular written instructions for completing the forms, which are revised periodically. When needed, field auditors provide additional instructions, in person or by telephone.

The Bureau of Research has responsibility for collecting and machine processing the monthly statistical report and schedules for the Federal study. Seven statistical clerks are employed in editing the monthly statistical reports and in transferring comparable information from records of the Bureau of Accounts to cases belonging to the Division of Child Guardianship. Incorrect or incomplete information is referred back to the relevant local welfare office for clarification. Monthly statistical report data are keypunched and verified by reference to a print-out of the punched cards.

Clerks in local welfare offices abstract records of the 5 percent sample of recipients under special study. Upon receipt in the Bureau of Research and Statistics, the abstracts are checked for accuracy and completeness--in part, by reference to records of expenditures in the Bureau of Accounts. The data are then transferred in coded form to schedules and identified by study number, name, case number, municipality, and program status in preparation for keypunching. Medical discharge diagnoses are coded according to the International Code of Diseases, Adapted. After keypunching, a consistency check is made from the card print-out to detect keypunching and/or coding errors.

The roll of payments form, collected monthly by the Bureau of Accounts for reimbursement purposes, is pre-audited. Then keypunched total amounts for each municipality are sent to the state treasurer for payment.

Aggregate counts, frequency distribution, and cross-tabulations of data on services and expenditures are prepared each month. The results appear in a stenciled Monthly Statistical Report and, ultimately, in the Annual Statistical Report issued by the Bureau of Research and Statistics. These reports assist administrators within the Department and fulfill Federal and state requirements for information. They are distributed to organizations and individuals upon request. Data collected for the Federal study of Medical Assistance undergo similar types of analyses annually.

Filing, Storage, and Use of the Information

Original report forms are generally filed by district and then by municipality within the district. Information collected by the Bureau of Research and Statistics is kept for about 10 years, except for data from ad hoc studies, which are kept indefinitely. The roll of payments, listing expenditures by name and social security number, is bound and filed for seven years in the Bureau of Accounts.

Punched cards, stored in the research or accounts processing areas, are kept for varying lengths of time. Cards processed for reimbursement are stored for about two years. Cards containing

monthly statistical information are stored until space limitations require disposal. Approximately 73,000 of these cards (200 cards for each of the 365 local welfare offices) are processed annually.

The Department of Public Welfare safeguards the confidentiality of individuals by aggregation of data in published reports. Requests for the use of information identifying individuals by name (as the roll of payments listing) are granted solely to authorized personnel engaged in research or other activities.

Problems

Staff shortages in local welfare offices affect data collection insofar as additional burdens are placed on available staff.

There is also difficulty in obtaining information from vendors. For example, vendors are remiss in completing the explanation of benefits form on clients billed under Medicare. Moreover, attempts to extend collection of discharge diagnosis information (presently limited to persons falling within the sample of the Federal study of Medical Assistance) to all Medical Assistance recipients receiving inpatient hospital care have been hindered by the reluctance of vendors to supply this information.

Additional Information Needed and Plans for Improvement

Additional information necessary for program planning and administration is obtained by means of special ad hoc studies of

samples of welfare clientele.[5] Information needs are fast-changing and vary in response to requests for information from Federal, state, and local authorities, as well as from the Department's administrators. In general, there is heavy reliance on indices generated by outside sources (e.g., census data, employment and social security benefits, and information made available by the Public Welfare Association and various Federal and state agencies).

Administrative changeover from local to state responsibility and control of welfare programs will enlarge the Department's supervisory role. It also will necessitate expansion of the fiscal record-keeping and processing operation.[6] Current efforts to organize 43 finance centers for making vendor payments and development of community service centers will bring about substantial

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[5]Generally, administrative approval is given for ad hoc studies when the entire Department agrees that a significant need for additional information exists. Studies concerned with medical assistance have been: Report of a Study of Appeals in Disability Assistance, which investigated a sharp increase in appeals in 1963-64; a drug study (May 1959), which looked into the variability of drug prices in order to establish a new drug price schedule; a dental study; and a study of doctors' fee schedules.

[6]No specific mention was made of the possibility of expanding the information system, in the near or distant future, to include routine collection of primary data on clientele. It was emphasized, however, that there are practical limits to the amount of information which could be collected by the staff of the Department on the very large number of welfare recipients and vendors. It was also stressed that the Department does not add to medical information furnished by providers of medical care; it pays providers for medical service rendered to welfare recipients.

CHAPTER XIII

UTILIZATION REVIEW AND PROVIDER SERVICE SYSTEM OF MASSACHUSETTS BLUE CROSS AND BLUE SHIELD

Introduction

Although Blue Cross and Blue Shield are separate organizations with independent boards of directors, they share data processing facilities and expenses. They provide service, under regular Blue Cross-Blue Shield coverage or Medicare, to between 60 and 75 percent of the population in Massachusetts that is hospitalized each year. Medicaid, administered by the Massachusetts Department of Public Welfare, covers the greater part of the remaining 25 to 40 percent. In 1966, Blue Cross alone had 3,100,000 subscribers, employed 1,161 full-time and 316 part-time persons, and spent $5,243,688.

The shared data-processing facility employed 182 full-time and 12 part-time persons and cost $1,377,166 to maintain. It had on-premise use of five IBM computers--including a 360-65, a 360-50, a 360-30, a 7074, and a 1401--and the usual complement of off-line card-processing equipment. The data-processing capability of this array of equipment far surpasses present levels of utilization.

Blue Cross has cooperated with virtually every hospital in the Commonwealth in establishing utilization review committees composed of physicians and hospital administrators. As a next step, it is starting a computer-based information system geared to utilization of hospitals and extended care facilities. Blue Cross is already a repository of basic information on the greater portion of the population hospitalized and/or served in extended care facilities each year in the Commonwealth. If successful in establishing a system for abstracting subscribers and nonsubscribers in a sufficient number of hospitals, it will become the best source of comprehensive health data on the population at risk. The potential of such a system for providing information relevant to planning and epidemiological research is unparalleled.

Utilization Review and Provider Service System

The Utilization Review and Provider Service System was designed to provide to hospitals and extended care facilities utilization review information for Medicare, administrative, and other needs relating to medical services. It became operational in six hospitals during the month of April 1968.[1] IBM 360 series computers are used to process abstracts of medical records of all discharged patients in subscribing hospitals. Abstracts of medical records of patients discharged during the month are forwarded by member hospitals to

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[1]Twenty-four more hospitals were expected to subscribe within the next six months. Extended care facilities will be added in 1969.

the Blue Cross data system for processing. In return, member hospitals receive a series of computer-produced reports.

After study of utilization review data forms used by HUP (Hospital Utilization Project), QUEST (Quality, Utilization, Effectiveness Statistically Tabulated Project), and PAS (Professional Activity Study), Blue Cross designed a medical record abstract form to secure the following information on every inpatient discharged during the month: identifying data (the hospital-assigned patient medical record number, health insurance benefit or Blue Cross certificate number, age, sex, racial origin, marital status, and residence zip code); diagnoses and operations (primary discharge diagnosis, other diagnoses, complications, and principal surgical or other procedures); type of medical service received; attending physician and other physicians; principal surgeon and other surgeons by specialization and certification; number of consultations; class of admission (e.g., emergency-accident, emergency-medical, or elective); use of special care unit; bed accommodation upon discharge, dates of admission, discharge and principal surgery; hour of admission; payment status; discharge status (e.g., routine, "left against advice," transferred, expired--not autopsied); type of medical facility to which transferred; and previous admission medical record number and date of discharge.

This information and the assigned hospital provider identification numbers are coded on the medical record abstract form by hospital medical record staff after patients have been discharged.

Pre-codes, coding convention charts (e.g., listing codes for types of service and for physician specialties), and the International Code of Diseases, Adapted for diagnoses, operations, and procedures guide the coding process. Formal and informal training sessions as well as written and oral instructions are provided to coding clerks. The hospital medical record librarian is responsible for supervising coders and for checking and verifying abstracts before they are submitted.

Abstracts are due on the 15th day following discharge. When received in the Blue Cross Data Control Department, they are manually prepared for keypunching.[2] Transmittal log entries record the dates on which abstracts were sent from the hospital and received at Blue Cross and the number of abstracts per hospital batch. After visual screening, abstracts are sent to the Blue Cross Data Preparation Department for keypunching; then they are returned to the Data Control Department.

Punched cards (three per abstract) are computer-validated to insure completeness and accuracy. They are checked for correct format, permissible values, and consistency prior to final processing. In the validation run, a tape file of valid abstracts is retained in the tape library. Invalid abstracts are identified on a validation error and control report which, along with the cards involved, are

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[2]This also includes a verfication check of coding on a sampling basis by the Blue Cross medical records librarian.

returned to the Data Control Department for correction and recycling. The Blue Cross medical records librarian reviews the print-out of errors for purposes of followup with hospital staff.

After validation, an updated abstract master tape file is created from which printed reports are produced for monthly distribution. Monthly reports sent to each member hospital include diagnosis, operation, and death listings and a discharge analysis. A quarterly index of physicians, semi-annual indexes of the monthly listings, and, from time to time, comparative studies will also be provided. Monthly reports will present for total samples various aggregate frequency distributions, cross-tabulations, and measures of association and variance. Special analyses of random and other user-defined samples are negotiable.[3]

Original abstracts are to be kept on file for six months in the Data Control Department; processed abstracts in tape form will be kept indefinitely. Access to the files of original abstracts is restricted to the medical records librarian and coding personnel of the Data Control Department for purposes of verification. Processed data will be used by Blue Cross personnel in various departments--most notably, statistical research, provider relations, and computer operations.

Hospital utilization committees, hospital administrators, medical record librarians, and authorized researchers can make use

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[3]Report content and format are still in the design stage. Systems analysts and researchers will help staff determine what kind of analyses and reports will prove most useful to individual subscribers.

of the data under controlled conditions. Subscriber hospitals, for example, can use data which they contributed to the system to conduct retrospective utilization review studies. They can also generate for administrative and accreditation purposes special reports and indices of medical services provided. In the aggregate, the data may be used for inter-hospital studies and for regional planning of medical care.

Problems

The first batch of abstracts processed during May indicated that coding errors exist in the data. This is not considered unusual at the beginning of any new data processing operation. Followup and increased familiarity with the coding system should enable coding clerks to reduce the number of errors.

Additional Information Needed and Plans for Improvement

Plans for gathering additional information are contingent upon the suggestions and decisions made by advisory committees, comprised of members of the utilization review committees, the administrative delegates of the hospitals, and representatives of planning and research agencies. Needs will determine whether additional information must be sought from sources outside the Blue Cross-Blue Shield system.

The Blue Cross Utilization Review and Provider Service System in Massachusetts will undoubtedly link with and become a part of

the national health information system to be developed under the Joint Long-Range Systems Planning Task Force of the Blue Cross Association and the National Association of Blue Shield Plans.

As announced in a July 2, 1968 release, "the joint project will enable the entire United States health-care system to use the vast potential of electronic data processing and high-speed communication."[4] Plans are "to develop an integrated information, record-keeping and data-processing system that can be adapted for use by all health agencies, providers, programs, and underwriters--both private and governmental." A planning council consisting of 13 representatives of Blue Cross and Blue Shield will direct the task force. Preliminary planning done by the National Association of Blue Shield Plans in a systems study assisted by Stanford Research Institute and by the Blue Cross Association led to creation of the council and task force.

Ability and Willingness to Participate in a Community-Wide Information System

Considering the ambitious undertaking of Blue Cross in Massachusetts and the still more ambitious project of the Blue Cross and Blue Shield national associations, inquiry into the ability and willingness of Massachusetts Blue Cross and Blue Shield to participate in a community-wide information system may appear somewhat anomalous. However, at the time this study was initiated,

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[4]News release of Blue Cross and Blue Shield national associations, dated July 2, 1968, Chicago, Illinois.

Massachusetts Blue Cross and its national organization had not embarked upon their ventures.

A headstart and experience in actually developing a computer-based health information system, with aspirations for total hospital and extended care facilities coverage in the Commonwealth, seemed likely to influence Blue Cross executive preferences. At the same time, the constraints which Blue Cross had to accept in order to start a system may help define limits which others must accept in designing a community-wide health and welfare information system.

If another health information system is to be developed in Metropolitan Boston, Blue Cross executives would prefer a computerized directory describing information which is stored in various organizations and which can be made available to authorized users. A central patient registry identifying patients or clients was not considered possible under present constraints. For this reason, the Utilization Review and Provider Service System does not obtain the names of patients whose records are abstracted.

In developing an archival information system containing abstracts of patient records, Blue Cross executives feel responsible for safeguarding the confidential data which it contains. They think this can best be done by controlling access and use. In this regard, they propose to review the policies of the Social Security Administration and the U.S. Census Bureau--policies which have gained

the confidence and acceptance of the general public.[5] In effect, Blue Cross personnel who are familiar with the available data will review with users their basic problems and the kinds of data they seek. Existing publications not known to the user may serve his purposes, in which case the relevant publication will be made available. In other instances, special tapes containing summary data or tabulations may be necessary.

To insure that the legitimate rights of individuals and organizations are protected, Blue Cross will plan a disclosure analysis and will withhold statistics which might otherwise appear in tabulations requested. Each table will be evaluated before and after tabulations, and appropriate editing principles applied. When authorized, users will be permitted data at cost.

All manipulation and processing of abstracts of patient records must be done on Blue Cross equipment under supervision of Blue Cross personnel. The Blue Cross Management Information System will contain data to which Blue Cross executives can turn for information upon which to base corporate decisions. From this system,

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[5]For a detailed statement of policies of the Social Security Administration and the U.S. Census Bureau governing access and use of data, see Some Statistical Research Resources Available at the Social Security Administration, Office of Research and Statistics, Social Security Administration, U.S. Department of Health, Education, and Welfare; "Policy Governing Access to Census Bureau Unpublished Data and Special Services," Data Access Descriptions, PA-1, Bureau of the Census, U.S. Dept. of Commerce, January 1968; and "Cost Considerations in Obtaining Census Bureau Data and Services," Data Access Descriptions, PA-2, Bureau of the Census, U.S. Dept. of Commerce, February 1968.

authorized users will be permitted anonymous data on Blue Cross personnel. Similarly, budgetary and operational data on programs and services will continue to be available as matters of public record.

Blue Cross executives were of the opinion that state or voluntary auspices could undertake development of a computerized information directory. Among alternative plans, the Health Planning Council of the Division of Administration and Finance, Executive Office of the Governor of the Commonwealth, the Metropolitan Hospital Planning Council, the Massachusetts Hospital Association, and United Community Services of Metropolitan Boston were explicitly mentioned. At the same time, universities were considered the most neutral of the various types of organizations which could undertake development of a computerized information directory.

In summary, Blue Cross has taken the lead in developing a computer-based health information system serving Metropolitan Boston. Blue Cross executives regard development of an archival type of health information system under Blue Cross auspices as natural in view of the breadth and depth of its involvement in the health care system. They feel that the Blue Cross health information system can expand where desirable to eliminate duplication of effort or develop interfaces with other computer systems to provide data bases at minimum cost. In fact, one contribution of a computerized information directory would be to identify overlap

and duplications in information now gathered separately by organizations in Metropolitan Boston and throughout the Commonwealth.

A directory, thoroughly documenting existing information, might also permit inference about what needs are not being met by present mechanisms for collecting data. Such knowledge would permit information systems designers to build and update systems by reference to the ongoing specifications of potential users and contributors. Development of a computerized information directory by another group in the community is viewed, therefore, as complementary to the Blue Cross health information system.

CHAPTER XIV

BUDGETARY AND SERVICE STATISTICS COLLECTION SYSTEM OF UNITED COMMUNITY SERVICES OF METROPOLITAN BOSTON

Introduction

United Community Services, in conjunction with the United Fund, plays an important role in health and welfare planning and coordination in Metropolitan Boston. In 1966, UCS expenditures totaled $6,542,249. Of this amount, $598,572 was spent on central administration, comprising planning, budgetary, internal accounting, and research functions. The remaining $5,943,677 was allocated to member agencies. UCS staff consists of approximately 43 professionals, 39 clerical and secretarial staff, and 18 building and luncheon personnel.

In its planning and coordinating role, UCS has cause to make maximum use of information gathered on voluntary health and social agencies and the populations they serve. It therefore maintains a budgetary and service statistics collection system to provide at least rudimentary data for planning and budgetary purposes. Study of this system illuminates the types and limits of knowledge presently available to guide decision making in the health and social welfare arena.

United Community Services of Metropolitan Boston routinely collects data from all UCS- and Massachusetts Bay United Fund-budgeted agencies. Two different but related operations, involving two departments, yield the requisite information.[1] The research department is charged with compiling annual service statistics, and the department of budgeting and administration with collection of a range of data on fiscal and program operations.

Service Statistics

For the purpose of planning and budgeting, UCS routinely collects annual service statistics on the 176 UCS-budgeted agencies and the 59 MBUF-budgeted agencies.

Agency service data include comprehensive descriptive information on each agency and its function, as well as the number of clients provided with direct services throughout the year. When processed, the data provide descriptive information and service statistics by agency location, type of service, and the number of individuals or families served by city or town of residence.

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[1] Information needs for program and regional social planning are met largely by numerous ad hoc studies conducted by the research department. Data needed by various divisions of UCS are gathered and compiled as prescribed by priorities, including continuing collection from year to year. One recent project analyzed data collected during 1965 and 1966 for construction of community profiles (the Community Research Project, conducted in collaboration with Combined Jewish Philanthropies). From this has come a completed study on the Negro population in Boston and a soon-to-be-released health study, which examines Boston health care needs and available health services. Another project involves the analysis of population characteristics and of the range of services available in various towns and MBUF planning areas.

Descriptive data on agencies are obtained from agency profile sheets, which request information on physical facilities, function, intake policy, fees, area served, and service trends. The number of different persons served in each city or town and the unit of count (individual or family) applicable to the number served are recorded by agencies on pre-coded town sheets.

Explicit written instructions are provided with the collection forms. They are completed by persons in the agencies responsible for compiling the requisite information. Although this information presumably exists in agencies in a form compatible with the request, tardy reporting makes it necessary to send reminder notices. Apparently, availability of information does not result inevitably in prompt reporting.

When received at UCS, forms are edited for completeness and accuracy by the research department. They are then coded and keypunched for processing on a Honeywell 16K computer made available by the United Fund. Computer print-outs list by town the agencies providing service, the number of persons served, and the types of services. Service statistics supply information needed by UCS and MBUF for budgeting, planning, and public relations.

Agency profile sheets have been compiled and filed for the past 10 years. They are used primarily by planning and research personnel within UCS and MBUF, but they are also sold to outside users.

Use of IBM cards provides greater flexibility in obtaining information from the town sheets. At the request of UCS and MBUF staff, the research department occasionally executes special runs to supply additional information needed.

Budget Information

Information collected concerning the 176 UCS-budgeted agencies includes an accounting of income from all sources and expenses for all activities within the organizations. It reflects transactions for the previous year, current operating budget, and requested amount for the next fiscal year. Additional budgetary information is gathered for certain agencies. This includes detailed information on visiting nurse visits (used to determine cost per visit) and, for camping agencies, per capita camper cost.

Annual budget report forms and quarterly financial reports are used to collect budgetary information. These forms request information on income and expenditures for activities applicable to specific types of agencies. Thus, somewhat different information is collected from hospitals, visiting nurse associations, scouting and campfire agencies, and other types of organizations.

Annual budget and quarterly financial reports are reviewed for mathematical accuracy by a budget analyst who compares the figures reported with agencies' audit reports.

Copies of the agency budgetary report forms are made available to members of the budget and allocating committee. Information contained therein is summarized in annual group budget reports.

Quarterly financial reports, recording actual income and disbursements, are used by the accounting staff to monitor the amount of agency expenditures. The research department and various planning divisions also refer to budgetary information.

Problems

Service statistics provide very gross and limited data. This is the result, in part, of depending upon information in the form in which it is collected by agencies. In the aggregate, the data are extremely variable--reflecting, for example, differences among agencies as they report the number of persons served annually. These are sometimes reported as counts of individuals and sometimes as families. It is not possible to determine where services are being provided in given small areas of communities because the data cannot be broken down by census tract.

Similarly, the types of services provided cannot be clearly delineated because definitions of service focus on the major function of agencies. Such definitions are too narrow and fail to represent the diverse functions of many agencies. If inaccuracies of reporting (e.g., reporting the number of visits instead of the number of different persons served as a unit count when the latter is requested) are to be overcome, a stringent monitoring system must be instituted.

Finally, the whole service statistics collection system needs revision. However, attempts by other councils of social agencies

to revise their systems have demonstrated how costly an undertaking it is. And once revised, there is no guarantee that reporting agencies will comply with requests for information any better under the new system.

Additional Information Needed and Plans for Improvement

Additional information necessary for administration and planning includes estimates of the number of persons in the community likely to need various types of service; the nature of existing services; characteristics of the actual recipients; population mobility patterns relating to inter-agency service utilization; the relationship between costs and services provided and between services and results; and social indicators useful for epidemiological purposes.

At present, data on the community and on agency services relevant to specific planning issues are collected on a project basis. Other information is obtained from documents of the U.S. Census Bureau, from city and town monographs, and from studies conducted by local public and private agencies. Research liaison with other agencies, involving joint collection or evaluation of data, expands and enriches data resources available to UCS research and planning staff.

UCS executives hope to improve and to expand the present service statistics collection system by taking steps to accomplish the following: (1) increase and expand liaison with other organiza-

tions undertaking systematic surveys of social and health problems in Metropolitan Boston; (2) join relevant information systems developed by other organizations; and (3) establish a computer-based information system for UCS member agencies. The success of the UCS-CJP Community Research Project encourages similar liaisons in the future. UCS plans to continue its relationship with the Resource Allocation and Priorities Assessment Project (RAPA) of ABCD under the following conditions: (1) if RAPA continues to receive funding; (2) if RAPA does not cost too much to operate; and (3) if RAPA's data collection system can be debugged to provide reasonably accurate data on participant agencies.

At the behest of 35 to 40 voluntary family service and child welfare agencies, UCS plans to establish a computer-based information system designed to meet the specifications of participant agencies. The system will have as a principal objective elaboration of a common data base to which participant agencies can turn for standardized computer reports on their service activities, distribution of fiscal and manpower resources, flow of expenditures, and the characteristics of the population served. The impetus for such a system comes from increasing demands on voluntary family service and child welfare agencies to improve internal planning and administration and to submit uniform reports to national organizations, of which they are affiliates, and to local planning organizations such as UCS.

As tentatively planned, the system will rely on a batch-processing computer. Participant agencies will submit data on sense-mark data sheets. The data sheets, in turn, will be read by an optical scanner and the information transferred to either magnetic tape or punched cards. The computer will be programmed to generate a series of standard and optional reports. Monthly batches of data sheets from participant agencies should prove satisfactory for maintaining an updated file structure.

The system will minimize the issues of client confidentiality by using agency-assigned identification numbers for unit processing. This, of course, precludes record matching and linkage between agencies. However, the system does not require inter-agency record linkage capability to achieve its principal objective of facilitating agency reporting of service and related statistics. For most planning and epidemiological research purposes, record-to-address linkage will suffice.[2] To achieve the latter capability, the system will attempt to incorporate exact address coding. But to the extent that reference to the address of single dwelling units can breach client confidentiality, constraints on exact address coding may have to be accepted.

At a later date, it may be possible to link functional budgets to the distribution of services within and across partici-

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[2]UCS executives have begun to lay the groundwork for record-to-address linkage and computer-mapping capabilities by petitioning the U.S. Census Bureau to create a DIME file of the Boston SMSA.

pant agencies. As yet, neither UCS nor any of its member agencies have established an accounting system which permits allocation of expenditures to agency functions. When changeover occurs, functional budgets can be entered into the system and linked to the rest of the data.

When the system has achieved its principal objectives of facilitating agency reporting, it can expand to create a capability for graphic display and computer mapping. Such capability, although enticing, is strictly "frosting on the cake." It simply makes information expressed in aggregate counts, frequency distributions, or measures of association more readily intelligible to wider audiences. It does not take away responsibility for explanation of meaning and interpretation of the limitations which accompany any set of empirically derived data. Stringent cost-benefits analyses will have to precede this phase of development if the system is to become self-supporting.

Self-support is an important consideration if the system is to survive, grow, and serve as a useful tool for planning and epidemiological research. Unfortunately, the histories of most grant-supported innovations have been short and demise has been related to the cessation of funding. From the outset, therefore, systems developers must maintain an uncompromising attitude toward costs in design and acquisition of equipment. Similarly, the expectation that participant agencies will share in the costs of

developing and maintaining the system has to be clear from the beginning. UCS executives feel the system can become self-supporting in five years or so.

Of necessity, participant agencies will have to work closely with systems developers in both the design and implementation stages. To this end, an advisory committee composed of executives and technical staff of UCS and participant agencies will be created. When data is requested by non-participant agencies and individuals, the advisory committee will have responsibility for judging each request on its merits and reaching a decision. In this way, client confidentiality and the legitimate rights of participant agencies to privacy will be protected. In any event, only aggregated data will be released. When special tabulations are necessary to satisfy requests, the cost will be borne by users at a rate sufficient to enable the system to break even, not only with respect to the special job but also in overall costs of maintaining the system.

Ability and Willingness to Participate in a Community-Wide Information System

UCS executives were of the opinion that their organization could most appropriately participate in a health and welfare information system which assumed the form of a directory of information stored in various agencies and available to authorized persons. In fact, UCS has already collaborated with Metrocenter at Boston University and with the Joint Center for Urban Studies

of MIT and Harvard University in such efforts. It also publishes listings of information available on operations of UCS and its financially participating agencies. UCS could expand this system in several directions without special consent of its board--and perhaps beyond with further authorization.

A central registry or exchange identifying patients and clients about whom additional information could be gained was judged "no longer relevant." UCS had recently agreed to the closing of the Social Service Exchange for this reason, thereby placing all responsibility for disclosure of client data, including the fact that a person is a client, back in the hands of direct-service agencies.

An archive in which abstracts of health and welfare agency records on clientele are stored, if it identified individuals by name, was objectionable for that very reason. On the other hand, the information system which UCS plans to create in collaboration with voluntary family service and child welfare agencies would constitute an archive without names. As such, it would avoid in large measure the issue of individual confidentiality. Even exact street addresses are to be safeguarded within the system by aggregating information over sufficiently large geographic areas to conceal the identity of specific addresses.

UCS executives were willing to consider sharing any information which they had collected. Actually, they had very little

data on patient or client characteristics in their possession. Individualized data on personnel were, in some respects, problematic. UCS has data of this type on its own personnel and on the employees of financially participating agencies. Although it was willing to report selected items on its own employees, it could not release information derived from the financially participating agencies without consulting them first. UCS could not presume to release information supplied for one purpose when approached for another purpose.

Budgetary and operational data on programs and services are, strictly speaking, not yet available because neither UCS nor its member agencies have operationalized accounting systems compatible with functional budgeting. UCS executives hope to establish functional budgeting within UCS and its member agencies, employing guidelines and standards developed by relevant national organizations. When established, they will have data which, under suitable safeguards, can be shared. They were willing to share any useable summary statistics which they possessed.

UCS executives thought it was unreasonable to assume that a single centralized data bank could be developed at this time to serve as a health and welfare information system for the Metropolitan Boston area. From all appearances, there would be a number of separate systems developed: one for state agencies which might, in turn, be composed of a number of individual

systems within state government; one for hospitals, through Blue Cross; and one for voluntary family service and child welfare agencies within UCS. Others might also emerge, but no reasonable likelihood was seen of merging these systems into a single central agency. The possibility of relating data across systems was considered the best that could be expected.

APPENDIX A

TENTATIVE LIST OF HEALTH AND HEALTH-RELATED AGENCIES TO BE CONSIDERED FOR INTERVIEWING BY THE MEDICAL FOUNDATION[1]

(As part of the Joint Center for Urban Studies Project for the Preliminary Design of a Health Information System for Boston)

I. MAJOR AGENCIES WITH A PLANNING FUNCTION RELATED TO HEALTH AND WELFARE[2]

A. Health Planning Agencies[3]

a. Official Agencies:

1. State Department of Public Health (several divisions)
2. State Department of Mental Health
3. Massachusetts Rehabilitation Commission
4. Massachusetts Vocational Rehabilitation Planning Project[4]
5. Boston Department of Health and Hospitals
6. Cambridge Department of Health and Hospitals
7. Massachusetts Health and Welfare Commission

b. Voluntary Nonprofit Agencies:

1. Massachusetts Blue Cross
2. Massachusetts Blue Shield
3. United Community Services (Health Division)
4. Hospital Planning for Greater Boston, Inc.

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[1]No distinction has been made in this listing between state-wide agencies and "local" (i.e., metropolitan-wide as well as single-community) agencies within the Greater Boston Area, even though the emphasis of the study is essentially in Greater Boston. This list was developed by E.B. Kovar, with advice and consultation from Dr. Leon Sternfeld.

[2]Some of these agencies obviously have a service component also, but are viewed in this list as being essentially "planning bodies"; no attempt has been made to indicate in this part of the listing which agencies should be interviewed although the Foundation may have to be selective.

[3]Those, i.e., with a specific health focus or component.

[4]Not a permanent agency, but currently engaged in "health planning."

Voluntary Nonprofit Agencies (cont'd)

5. Greater Boston Hospital Council
6. The Medical Foundation
7. Regional Medical Program (Tri-State Heart-Cancer-Stroke Program)
8. Massachusetts Hospital Association
9. Massachusetts League for Nursing
10. State Federation of Nursing Homes
11. Mental Health Planning Committee of Metropolitan Boston[5]
12. Affiliated Hospitals Center (Harvard Medical School Hospitals)

B. Generic Planning Agencies with a Health-Related Interest

a. Official Agencies:

1. Governor's Board of Economic Advisers
2. State Department of Commerce (several divisions)
3. State Department of Public Welfare
4. Boston Department of Public Welfare
5. Metropolitan District Commission
6. Boston Housing Authority
7. Metropolitan Area Planning Council[6]
8. State Department of Natural Resources
9. Boston Redevelopment Authority
10. Boston "Model Cities" Planning Council[7]
11. State Division of Administration and Finance[8]

b. Voluntary Nonprofit Agencies:

1. Action for Boston Community Development
2. United Community Services (planning divisions other than health)
3. City Planning Departments (Harvard and MIT)
4. Joint Center for Urban Studies (Harvard and MIT)
5. Metrocenter, Boston University

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[5] A planning "body"--though not an agency--co-sponsored by UCS, the State Dept. of Mental Health, and the Mass. Association for Mental Health.

[6] Set up, in part, like a voluntary agency, but represents officially the city and town authorities of Metropolitan Boston.

[7] Soon to be set up, if grant is forthcoming, though not now in operation.

[8] Contains Bureau of Hospital Costs and Accounts, as well as new office designated by the Governor as the comprehensive health planning authority for the State.

II. AGENCIES FUNCTIONING ESSENTIALLY AS SERVICE PROVIDERS[9]

A. Health Service Agencies

a. Official Agencies

1. Brookline Health Department
2. Newton Health Department
3. Combined Health Departments of Weston, Needham, Wellesley[10]
4. Approximately 70 other local health departments
5. V.A. Hospitals
6. Metropolitan State Hospital
7. Quincy City Hospital
8. Other county and state hospitals and sanatoria
9. State Boards of Registration and Licensure[11]

b. Voluntary Nonprofit Agencies:

1. Hospitals (Teaching)[12] --Beth Israel, Boston Woman's*, P.B. Brigham, R.B. Brigham*, Children's*, New England Medical Center*, Hebrew Rehabilitation Center, Mass. Eye and Ear*, Mass. General* (includes McLean), Mass. Mental Health Center, New England Baptist*, Deaconess, St. Elizabeth's, University*, Newton-Wellesley*.

2. Hospitals (Community) --Approximately 40 community general hospitals (plus several college infirmaries) within the S.M.S.A., of which 6 are in the city of Boston proper. The following institutions in this group can be considered possible key ones for purposes of the feasibility study:

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[9] Some, or even many, of these agencies, of course, having a planning component also, but are viewed in this context as providers of service.

[10] These three departments are combined only in the sense that they share the time of a non-medical health officer in common.

[11] Approximately 18 in the health field, under the aegis of the State Division of Registration.

[12] Medical School affiliation.

* Receive financial support through UCS from the United Fund.

Beverly	Mt. Auburn (Cambridge)
Carney (Boston)	Lynn
Faulkner (Boston)	Malden
St. Margaret's (Boston)	Salem
Parker Hill Medical Center (Boston)	South Shore (Weymouth)
	Waltham

3. Other (Special) Hospitals and Clinics--Jewish Memorial, New England Sinai, J.P. Kennedy Memorial, Holy Ghost, Washingtonian, Boston Evening Clinic, Lahey Clinic.[13]

4. Visiting Nurse Associations--Approximately 50 within the S.M.S.A., of which 29 receive financial support from the United Fund through UCS. Those that perhaps should be interviewed are:

   --Boston V.N.A. (top-flight city-wide service, with regional offices)
   --Brookline V.N.A. (closely coordinated with town health department)
   --Newton V.N.A. (good service in middle-sized suburban city)
   --Everett V.N.A. (good service in poor area)
   --Winchester V.N.A. (good generalized service)
   --Combined V.N.A. of Reading-Woburn-Stoneham-Wakefield (recently amalgamated agency from four independent ones)
   --Social Service League of Cohasset (combined public health nursing and family service agency)
   --Dover-Medfield-Norfolk V.N.A. (small regionalized service for approximately 15,000 persons)
   --Any one of the small one-or-two-nurse agencies for purposes of comparison.

5. Mental Health Associations and Clinics[14]

   --Massachusetts Mental Health Association**
   --Judge Baker Guidance Center**
   --Putnam Children's Center
   --Douglas Thom Clinic for Children

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[13] Affiliated with New England Baptist Hospital.

[14] Includes state-aided clinics, most of which, however, are affiliated with local voluntary mental health associations and which are included under the voluntary listing.

**A select group of those that might be interviewed.

Mental Health Associations and Clinics (cont'd)

--Wellesley Human Relations Service**
--Beaverbrook Guidance Center (Belmont area)
--North Suffolk Mental Health Center**
--Dorchester Guidance Center
--Judge Stone Clinic (Brockton)[15]
--Brookline Mental Health Center**
--Cambridge Guidance Center**
--Newton Mental Health Center
--Malden Mental Health Center
--Somerville Child Guidance Center**
--Walden Clinic (serves Concord and Lincoln)
--Framingham Mental Health Center
--Mystic Valley Children's Center (Lexington Area)
--Lowell Mental Health Center** (serves Wilmington)
--South Shore Mental Health Center[16]
--Leslie B. Cutler Clinic (Norwood-Needham-Dedham Area)
--Eastern Middlesex Guidance Center (Melrose-Wakefield Area)
--Greater Lynn Mental Health Center
--North Shore Mental Health Center**[17]

6. Categorical Health-Education, Rehabilitation, and Research Agencies[18]--Guild for the Hard of Hearing, Adult Blind Association, Epilepsy Society, Arthritis Foundation, Diabetes Society, Alcoholism Committee, Community Workshops, state and local heart associations, state and local tuberculosis associations, state and regional cerebral palsy associations, Boston Aid to the Blind, Catholic Guild for the Blind, Protestant Guild for the Blind, small self-help organizations (e.g., Q.-T., Myasthenia Gravis Society), state and local cancer societies, Speech and Hearing Foundation, Center for Blind Children, Easter Seal Society, Robbins Speech and Hearing Clinic, Forsyth Dental Infirmary, Planned Parenthood League, etc., state and local retarded children's association (especially Boston Association for Retarded Children).

**A select group of those that might be interviewed.

[15]Serves Marshfield, Duxbury, Hanover, Norwell, Pembroke, Holbrook, and Rockland.

[16]Serves Quincy, Braintree, Cohasset, Hingham, Hull, Scituate, Weymouth, Randolph, and Milton.

[17]Serves Beverly, Danvers, Hamilton, Manchester, Marblehead, Middleton, Peabody, Salem, Topsfield, Wenham.

[18]Sampling of this group for interviewing will be an extremely difficult job in view of their variability with respect to auspices, level of service.

c. Academic Agencies:[19]

1. Medical schools and medical centers (three)[20]
2. Schools of nursing (3 collegiate programs; approximately 20 hospital schools; several associate-degree schools; schools of practical nursing.
3. Harvard School of Public Health
4. Laboratory of Community Psychiatry
5. Law-Medicine Institute of Boston University
6. Northeastern University (special training program in health field)

d. Proprietary and Commercial Health Agencies:

1. Some 300 or so nursing homes (mostly proprietary) in the Greater Boston Area
2. Private laboratories
3. Private pharmacists
4. Private General Hospitals
5. Private Mental Hospitals and Sanatoria

B. Non-Health Service Agencies with a Health Concern or Component

a. Official Agencies:

1. State Civil Service Commission (re: manpower recruiting, etc.)
2. State Rate-Setting Commission for Nursing Home Reimbursement
3. Local public welfare departments
4. Local veterans' services

b. Voluntary Nonprofit Agencies:

1. Goodwill Industries
2. Salvation Army
3. Red Cross (central office and chapters)
4. Independent Homemaker and Home Health Agencies (e.g., Inter-Community Homemaker Service)
5. Multi-Service Centers for Health and Welfare Services (Roxbury; Kennedy in Charlestown, etc.)

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[19] Universities and colleges that have--or have begun to have--a health-service component. Of course, these are "voluntary" agencies, for the most part, but not set up to give service to the general public, as such.

[20] Includes Columbia Point Comprehensive Health Center (Tufts) and Roxbury Comprehensive Health Center (Boston University).

Voluntary Nonprofit Agencies (cont'd)

6. Local community action programs of O.E.O. (APAC's) in areas of Boston and in communities outside of Boston
7. Boston Social Service Exchange
8. Family Service Agencies (especially Boston Family Service, Catholic Charitable Bureau, and Family Counseling and Guidance Services)
9. Children's Agencies (especially Boston Children's Service Association and M.S.P.C.C.)
10. YMCA's and YWCA's
11. Boys' Clubs and Girls' Clubs
12. Selected settlement houses and settlement federations (especially United South End Settlements and Roxbury Federation of Settlements)
13. Combined Jewish Philanthropies

c. Academic Resources:

1. Schools of Social Work (three)
2. Schools of Business Administration (Harvard, Boston University)
3. Departments of Sociology
4. Etc.

d. Proprietary and Commercial Agencies:

1. Insurance Companies--John Hancock, Prudential, New England Mutual, Liberty Mutual, etc.
2. Consultant Firms[21]--Arthur D. Little, Social Dynamics, etc.

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[21]Doing consultant work in health and developing health information statistics.

APPENDIX B

SAMPLE LETTER TO EXECUTIVES OF HEALTH AND HEALTH-RELATED AGENCIES

Dear_____:

Several months have passed since the inception of the Health Information System Feasibility Study. We have learned a good deal about record-keeping and data processing in health and related agencies in Metropolitan Boston. Your cooperation and interest have made our progress to date possible.

As we enter the final stages of study, several salient issues remain to be explored. We feel new information services, organizations, and systems will be most usefully and economically designed if potential users and contributors are represented in the design and planning stages. We wish, therefore, to represent as accurately as possible your ideas and preferences as potential users and contributors in our report with recommendations to the U.S. Public Health Service.

A computer-based health/welfare information system serving authorized administrators, planners, practitioners, and researchers in Metropolitan Boston could take one or more of the following forms:

a. A directory of information stored in various agencies which could be made available to authorized persons.

b. A central registry or exchange identifying patients and clients on whom additional information could be obtained directly from the organizations serving them.

c. An archive in which abstracts of health, welfare, and social agency records on individuals served are stored.

1. Could your organization presently participate in a health/welfare information system assuming any of the aforementioned forms? If your organization could not participate in a system under one form or another, why is this so? What would have to be done to permit participation?

2. Which of the following types of information could your organization contribute to a health/welfare information system, whatever its form? If your organization cannot contribute one or more items below, why is this so?

   a. abstracts of patient or client records

   b. individualized data on personnel

   c. budgetary and operational data on programs and/or services

   d. summary statistics covering any of the aforementioned items

3. Under what auspices do you think a computer-based health/welfare information system serving Metropolitan Boston could best be developed? Is it preferable that some branch of government--Federal, state, or local--initiate a system? Or would development under voluntary auspices be preferable? Is there a particular organization or combination of organizations in the Commonwealth which appear more appropriate than others to undertake development of a computer-based health/welfare information system?

If you have ideas, preferences or policies relating to these questions, you can assist us once more by addressing yourself to them as administrator, planner, practitioner, and/or researcher, as the case may be. You may wish to confer with members of your board and staff before replying, since the questions may impinge upon organizational policy.

I shall be looking forward to your reply. Please feel free to call if you have questions or desire further explanation. Again, thank you for past cooperation and interest and your attention to the present inquiry.

Sincerely yours,

John H. Noble, Ph.D.
Project Director
Health Information Study

APPENDIX C

CODE FOR RECORD FORMS

7/1/68
8/18/68

Item	Column	Code
Organization	1,2	01 Associated Catholic Hospitals 02 Blue Cross 03 Boston Dept. of Health and Hospitals 04 Children's Hospital Center 05 New England Medical Center Hospital 06 State Dept. of Public Welfare 07 United Community Service 08 Venereal Disease Division (State P.H.D.) 09 Vital Statistics (State P.H.D.)
Identification Number	3,4,5	As assigned
Specific Type of Form	6,7	01 Application for Admission, Registration, or Discharge 02 Application for Reimbursement 03 Authorization for Reimbursement 04 Medical, Epidemiological, Case Record, or Report of Diagnosis (Individual) 05 Record of Test Results, Procedures Request for Tests 06 Registration Card, Face Sheet 07 Report of Disease Occurrence, Dog Bite 08 Report, Record of Status, Condition (Immunization, Vital Statistics) 09 Budget and/or Financial Report 10,13 Summary, Evaluation, Survey Report of Service Data, Services Provided (Institution, Program), Transfer Sheet 11 Blood Bank Credits 12 Bill or List of Charges 14 Other 98 Unclear 99 No Information

* Provisions for charges provided on the forms,

Item	Column	Code
Subject or Title of Form	8,9	01 Lab Reports: Hematology; Microbiology; Urinalysis; Biochemistry; Spinal Fluid; Surgical Pathology; X-Ray; Urine and Pregnancy Test; Misc. Lab Requests 02 Blood Bank; Blood Bank Credits 03 Specific Charges: Inhilation Therapy; Pharmacy (O.B.S.); Solutions and I.V. Sets; Central Service; Delivery Room; Cardiopulmonary Lab.; Physical Therapy; Misc. Charges and Credit 04 Discharge and Transfer Notice 05 Home Health Agency Report (Medicare) 06 Outpatient Hospital Billing (also Medicare) 07 Inpatient Hospital Admission and/or Billing (also Medicare) 08 Blue Cross: Inpatient Admission; Extended Benefits Claim; Physicians Certification; Blue Cross Data Service Report 09 Rabies Control Report Form 10 Tuberculosis: Report; Diagnosis; History; Clinics Service Report; Hospital Admissions and Discharge; Application for Admission; Summary Data Transfer Sheet 11 Communicable Disease Report 12 General Information Interchange 13 Case Records: Acute Enteric Disease; Encephalitis, Meningitis 14 Hepatitis Questionnaire 15 Advance Registration (Hospital Admission) 16 Admission Record Outpatient; Short Term Admission 17 Nurses Notes; History Sheets; Medication Administered 18 Clinic Sheets: Regular Clinic; Emergency Clinic; Outpatient; Surgical Outpatient

Item	Column	Code
Subject or Title of Form (Cont.)	8,9	19 Emergency Record 20 Statistics: Emergency Service; Clinics; Pediatric Ambulatory; Adult Clinic 21 O.A.A., M.A.: Vender Medical Payments, Social Data 22 D.A.: Report of Medical Vender Payments 24 A.F.D.C.: Medical Vender Payment Report; Family Eligibility Form 25 Social Data Cards: Transfer Sheets, Referrals 26 D.A. Recipient Budget (Persons Covered) 27 Summary Reimbursement Claim, Roll of Payments 28 Statistical Reports: General; Monthly; M.A. 29 Annual Budgets: Girl Scouts; Boy Scouts; St. Vincent de Paul; VNA; Standard Budget 30 Quarterly Budgets: Boy Scouts; Girl Scouts; St. Vincent de Paul; VNA; Standard Budget 31 Venereal Disease: Registration; Report; Diagnosis; Epidemiological Report 32 Birth Certificate 33 Death Certificates: Fetal Death; Standard Death; Medical Examiner's Certificate 34 Marriage Certificate 35 Service Statistics Summary 36 Agency Description 98 Unclear
Area Covered by Form	10	0 Not Applicable (No Area Relation) 1 Intra-organizational 2 State 3 Region 4 City, Town 5 Close-ended (Multiple Alternative) 9 No Information
Date of Last Revision	11,12	Report by Year-Last 2 Digits 99 No Information
Names of Individual, Institution, Program, or Area Covered by Report	13	1 Yes 2 No Information

Item	Column	Code
Address of Individual, Institution or Program	14	0 Not Applicable (Summary Sheets, Statistical Aggregations) 1 Street, City, State 2 State Only 3 City Only 4 Open-ended 6 Other 5,9 No Information
Telephone Number of Individual, Institution, or Program	15	0 Not Applicable 1 Yes 2 No Information
Age of Individual	16	0 Not Applicable 1 Exact Birth Date (Yr., Mo., Da.) 2 Age Groupings 3 Age as of Last Birthday 4 Month and Year Only 5 Open-ended (Just ask for Birth Date) 6 Other 9 No Information
Birthplace (Individual)	17	0 Not Applicable 1 Open-ended (General Answer) 2 Citizen (U.S. or Not) 3 State 4 City and State 5 Country of Birth Only 6 Other (Hospital, etc.) 7 Close-ended (City, State, Country, Hospital) 9 No Information
Marital Status (Individual)	18	0 Not Applicable 1 Open-ended 2 Close-ended 3 Other 9 No Information
Sex	19	0 Not Applicable 1 Yes 2 No Information
Race (Individual)	21	0 Not Applicable 1 Open-ended 2 Dichotomy (White, Other) 4 Trichotomy (White, Black, Other) 5 Extensive List to Choose From 6 Other 9 No Information

Item	Column	Code
Religion (Individual)	20	0 Not Applicable 1 Open-ended 2 Close-ended 3 Religion and Clergyman 4 Religion, Church, and Clergyman 5 Other 9 No Information
Social Security Number	22	0 Not Applicable 1 Yes 2 No Information
Education (Individual)	23	0 Not Applicable 1 Total Years Completed 2 Last Grade Completed 3 Degrees, Certificates Attained 4 Other 9 No Information
Occupation/Employment (Individual)	24	0 Not Applicable 1 Occupation: Close-ended 2 Occupation: Open-ended 3 Dichotomy (Employed: Yes, No) 4 Trichotomy (Employed, Unemployed, Retired) 5 Place of Business, Occupation, Employer 6 Usual Occupation 7 Other 9 No Information
U.S. Military Service (Individual)	25	0 Not Applicable 1 Veteran: Yes, No 2 Draft Status 3 Other 9 No Information
Weight	26	0 Not Applicable 1 Yes 2,9 No Information
Height	27	0 Not Applicable 1 Yes 2,9 No Information
Next of Kin (Responsible Individual)	28	0 Not Applicable 1 Yes 2,9 No Information

Item	Column	Code
Name of Spouse or Parent (Individual)	29	0 Not Applicable 1 Yes 2,9 No Information
Date of Application, Admission, Visit, Report, Program, etc.	30	0 Not Applicable 1 Yes 2,9 No Information
Diagnosis (Individual)	31	0 Not Applicable 1 Open-ended 2 Close-ended (International Code) 3 Close-ended (Other) 9 No Information
Name of Person Filling Out Form	32	0 Not Applicable 1 Yes 2,9 No Information
Position of Person Filling Out Form	33	0 Not Applicable 1 Yes 2,9 No Information
Intra-organizational Code No., Index No., Case No., Serial No., Patient No., Form No.	34	0 Not Applicable 1 Yes 2,9 No Information
Treatment Prescribed (Individual)	35	0 Not Applicable 1 Yes 2,9 No Information
Tests, Cultures Made, Medicine Prescribed (Individual)	36	0 Not Applicable 1 Yes 2,9 No Information
Record of Previous Visits to Same Unit of Organization	37	0 Not Applicable 1 Yes 2,9 No Information
Criminal Record	38	0 Not Applicable 1 Yes 2,9 No Information
Record of Previous Hospitalization, or Institution or Agency Involvement	39	0 Not Applicable 1 Yes 2,9 No Information

Item	Column	Code
Charges Listed	40	0 Not Applicable 1 Yes 2,9 No Information
Health Insurance Coverage (Individual) Blue Cross called for specifically with I.D. No. use column 42- Otherwise, Leave Blank	41,42	0 Not Applicable 1 Yes, Open-ended 2 Close-ended 3 Blue Cross and No. 4 Other 9 No Information
Address and Phone No. of Next of Kin or Responsible Person	43	0 Not Applicable 1 Yes: Address and Phone 2 Address Only 3,9 No Information

APPENDIX D

HEALTH INFORMATION STUDY TELEPHONE SURVEY

Agency:_____ Type:_____
Address:_____ Tel.:_____ Ext.:____
Chief Administrator:_____
Data Processing Personnel:_____ Title:_____
_____
_____

COMMENTS:

1. Does your organization have a full- or part-time person or dept. whose primary responsibility is record-keeping & data processing?
   - Dept._____
   - F.T. _____
   - P.T. _____
   - No _____

2. May we have the name & your approval to contact the dept. head(s) (FT/PT person) for further information in the future if necessary?
   - Yes _____
   - No _____
   - Name _____
   - _____

3. How many employees does the dept. head (FT/PT person) have under his supervision in discharge of his responsibilities?

Dept. (FT/PT)	# Employees
_____	_____
_____	_____
_____	_____
_____	_____

4. Approximately how much ($) did your organization spend last fiscal year on record keeping & data processing?

Dept. (FT/PT)	Dollars
_____	_____
_____	_____
_____	_____

5. Does your organization use automatic data processing equipment & materials such as:

	Yes	No
Mc Bee Cards	__	__
IBM Cards	__	__
Key Punch	__	__
Sorter-Counter	__	__
Computer(s)	__	__

Computer brand & model
_____

6. What is your organization's policy about making information on patients/clients available to other agencies and/or individuals?

7. Have you entered into any special agreements with other agencies about sharing information on patients/clients? If yes, which agencies?

Yes___ Which Agencies?
_____
_____
_____
No ___

8. Would you please send us a copy of your most recent annual report?* Send to:
Dr. John Noble
The Medical Foundation
29 Commonwealth Avenue
Boston, Mass.

Yes___
No ___

*If reluctant about sending annual report, ascertain following information:

a) Total No. of persons served last year: _____
b) Total No. of employees: _____
c) Most recent budget total: $_____

APPENDIX E

IN-DEPTH RECORD MANAGEMENT INTERVIEW GUIDE

Agency:_____Telephone No.:_____

Address:_____

Respondent:_____Area/Dept.:_____

_____ _____

I. 1. What information is now gathered?

Individual_____ Institution_____ Program_____

Identifying:
Name_____ Address_____ Tel. No._____ Birthdate____Age____Sex____
Birthplace____ Marital Status____ Religion____ Name of Spouse (or parent)____ Social Sec. No.____ Occupation/Employment____
Employer____ Race____ Education____ U.S. Military Service____

Date of:
Application____ Admission____ Visit____

Diagnosis (or treatment)____ Results of Tests or examinations____

Referrals____

Capacity of Institution/Program:
Quota____ Bed Capacity____

Measure of Service:
patients served____ # beds used____ # contacts made____
Allotments of beds, service____ # tests made____ # drugs dispensed___
people served____ Other____

Measure of Outcome:
cases discharged____ # people referred____
Tests: # positive____ # negative____ # deaths____ # violations____
Other____

2. (a) By whom? Who actually fills out the forms?

Self (patient)_____ Physician_____ social worker_____
nutritionist_____ sanitarian_____ clerk_____ volunteer_____
other_____

(b) At what stage(s) of patient/client processing?

3. Under what conventions and definitions? (Sample of forms used)

Specific type of form:
Record of disease, diagnoses, results of tests or examinations_____
Admission Record_____ Case Record_____
Fiscal accounting--Application for service payment_____

What methods are used to instruct recorders and what is the extent of supervision?
Oral directions_____ Written instructions_____
Training session(s): Formal, informal_____ Type & frequency of supervision:_____

4. What checks are taken for verification for accuracy and/or completeness?

5. What are the stages and type of filing?

6. Under what conditions is the record referred to? By whom? (type of users)

7. Editing and coding
   (a) Are date and/or receipt of record used to exert control over processing?_____

   (b) Who checks for accuracy and completeness, and how is followup on missing or incorrect data handled?

   (c) Is data coded?_____ By whom?

   Which items are coded?

   How: pre-coded, coding manual, etc.

What measures are taken to verify coding?

What percentage of cases?

8. Data Analysis

(a) Methods:

hand tallies ____
McBee cards ____
IBM cards ____

(b) Type of analysis:

counts of aggregates ____
frequency distributions ____
cross tabulations ____
measures of association and variance ____

(c) Nature of sample:

universal____ sample____

What sort of sampling design?

9. (a) Where and for how long is the information collected stored?

(b) In what form? (original form, cards, tapes, disc memory)

(c) Does it appear in summary form in reports, etc.? (Name and sample copy)

(d) For whose and what purposes?

10. Problems
Staff (number, training), finances, equipment, etc.

Reports are: simply typed_____ stenciled_____ printed_____

II. 1. What additional information do the organization's administrators and planners now seek relative to the area/dept. studied?

2. (a) How much of this information must necessarily come from outside sources?

(b) Which sources?

(c) How is it currently obtained? (special surveys, etc.)

(d) Under what arrangements? (outside contracts to which agencies, etc.)

III. What are the future plans for elaborating the information system (esp. computer based)?

R30
N

Noble, John H. Jr. etal

Feasibility of Developing a Computer-Based Health & Welfare Information System for Metropolitan Boston.

DATE	ISSUED TO